A COOPERATIVE SELF-SUPPORT SYSTEM FOR SEVERELY PHYSICALLY DISABLED YOUNG ADULTS

A Final Project Report

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This work was supported in part by the RSA grant 13-P-55487/6-01 (D-HEW) and with additional funding from Research and Training Center RT-4, and from an establishment grant provided by the Texas Rehabilitation Commission.

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Foreword

This report examines both the development and the consequences of a cooperative self-support residential system for severely physically disabled young adults. The Cooperative Living project resulted from the efforts of many people who believed that alternatives could be established to provide independent living settings for physically handicapped persons. As one such alternative, the project constituted an experimental intervention into the lives of 40 severely physically disabled young adults. Most of the residents were in the 20 to 30 age group, all were single, and each resident used a wheelchair as his means of mobility. These persons had no use of their legs and minimal use of their arms and hands. Before entering the project, they had lived with their parents or had been confined to nursing homes or hospitals. The changes that have occurred in their lives have been dramatic.

The Cooperative Living program was conducted as a three-year Research and Demonstration Project with support from RSA grant 13-P-55487/6-01 (D-HEW) and with additional funding from Research and Training Center RT-4, and from an establishment grant provided by the Texas Rehabilitation Commission.

Part I of this report presents the background, the need for the study, the purpose of the project, and the objectives. Part II deals with the internal aspects of the Cooperative Living system and describes the resident population. Part III presents the research methodology and the findings. Part IV discusses further expansion of the Cooperative Living concept. Part V directs attention to special considerations and dimensions considered important in developing living arrangements for persons with severe physical impairments. An epilogue returns the focus of the report to the level of the individual and follow the courses the 40 residents have taken since the project began four years ago.

The authors wish to acknowledge with deep appreciation the contributions and efforts of the following people and agencies for their cooperation and support in successfully completing this project.

The Houston Housing Authority
Mr. Thomas Booker, MSW, Executive Director (Retired)
Mr. Leal Sherman, MSW, Assistant to the Executive Director

The Texas Rehabilitation Commission
Mr. Jess Irwin, Commissioner
Mr. Doyle Wheeler, Deputy Commissioner
Mr. John Fenoglio, Director, Vocational Rehabilitation
Mr. Ted Thayer, Program Specialist for the Severely Disabled

The Texas Institute for Rehabilitation and Research
Dr. William Spencer, Director
Dr. R. Edward Carter, Associate Director, Clinical Services
Dr. Marcus Fuhrer, Director of Research
Ms. Joyce Salhoot, MSW, Director of Social Work Services
Ms. Nita Weil, Director of Volunteers
Dr. Shalom Vineberg, Consultant

Cooperative Living Project Staff
Ms. Delle Shaw, Administrative Assistant
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Mr. Lex Frieden, Resident Council
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Mr. Ed Rhame, Resident Council
Mr. Vernon Dement, Resident Council
Mr. Richard Wilson, Resident Council
Mr. Ken Arnold, Resident Council

Rehabilitation Services Administration
Mr. Paul Thomas, Project Officer

Finally, special thanks and appreciation are given to the Cooperative Living residents who shared in the development of the project and whose experience has led to the creation of new opportunities for other handicapped individuals.

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June, 1977

PART I: BEGINNINGS

Chapter 1: *Introduction*

- The Problem
- Review of Past Experience
- The Project
- The Project's Goals
- Preliminary Planning
- An Environment

The Problem

Rehabilitation personnel have been concerned for years about the large number of physically disabled persons who quickly begin lives of isolation and dependency after discharge from rehabilitation programs. This occurs even though these individuals may possess good educational and vocational potential and have been equipped with skills and devices for self-help. If the rehabilitation goal of active, productive living is to be achieved, the severely physically handicapped person must be integrated into the community and must simultaneously be offered continuing medical care and opportunities for education, job training and placement. These goals of independent and productive living have been achieved thus far by only a small number of catastrophically injured persons, however, because there are serious limitations in the availability of necessary living arrangements and supportive services such as attendant care and transportation, key elements in successful integration.

The consequences of limited resources are all too clearly demonstrated by countless young disabled persons who are confined to nursing homes or are isolated in home settings where there are no opportunities for participation in the mainstream of society. Until special housing arrangements are available, catastrophically injured persons with vocational potential who have physical care support needs and unique living requirements will not be allowed to become vocationally productive. Due to an absence of community-based options, our system of services will continue to relegate those persons with limited potential to institutional confinement. The institutional life-style has been well addressed by many handicapped people who state the limited options available in an institutional setting are both unnatural and undesirable.

It is important to recognize at the outset that disabled persons differ greatly in their level of physical functioning, in their personality traits, and in their pre-disability life-styles. Consequently, their housing needs are diverse. Many disabled persons are able to become entirely independent in residential structures designed for wheelchair accessibility, others have functional limitations so severe that physical assistance in day-to-day activities is necessary. The physical assistance needed by persons who are medically stable should be clearly distinguished from nursing care that is provided in institutional settings. The focus of this project is on housing opportunities for persons who have significant limitations in performing activities which necessitate daily living assistance in transferring from bed to wheelchair, eating, dressing, and performing other personal needs.

According to most gross estimates, 2.5% of the United States population has a physical condition or impairment that would be termed a disability. The severely disabled homebound or institutionalized population is estimated at .5–1.0% of the general population. For a broader view, those persons with significant limitations in mobility and in performing activities of daily living may be as high as 5% of the total population. This estimate

will vary, however, depending upon the age range being considered.* In a recent study (1975) by the Urban Institute, Washington, D.C., the most severely disabled population aged 18-64 was placed at 4.2 million persons.**

Difficulty in finding an acceptable place to live with an emphasis on needed supportive services is thus shared by thousands of individuals with varying degrees and types of disabilities. Offering community-based alternatives to institutional confinement must become a goal. Rehabilitation must extend beyond the institution.

Review of Past Experience

At the time the Cooperative Living project began in January, 1972, there were few housing programs for physically handicapped persons in the United States and little written material available on this subject. Awareness of the housing issue has grown significantly in the succeeding five years, and some progress has been made in increasing the number of living arrangements available. Literature in this field covers a number of different areas. The following summary is not intended to review the literature exhaustively but rather to delineate some of the approaches used to address the housing needs of the severely physically handicapped.

Surveys of housing needs of the physically handicapped population have been done in various locations (see, for example, Fenton, 1972; Fishman, 1971; California State Department of Public Health, 1969; Bartels, 1970). Efforts have also been made to survey and document the existing alternatives available (Laurie, 1973; Fay, 1975).

In providing suitable housing, one fundamental aspect of the problem is the provision of appropriately-designed physical structures. Work has been done on general design criteria (see, for example, Contract H-2200R, U.S. Department of Housing and Urban Development, 1975). A number of accessible apartments have been built with HUD support including Highland Heights, Fall River, Massachusetts; New Horizons Manor, Fargo, North Dakota; and Independence Hall, Houston (Lavine, 1974). Smaller-scale solutions to physical design problems have also been developed by private organizations and by commercial developers. Several states, such as Massachusetts, have enacted standards and enforcement mechanisms insuring accessibility in residential structures (Michel, 1972).

The provision of supportive services such as attendant assistance and transportation is a second basic element in housing. The significance of

*Spencer, W.A.; Stock, D.D.; Cole, J.A., *Medical Rehabilitation and Medical Care of the Chronically Ill*, 1976. (Unpublished manuscript)

**_Report of the Comprehensive needs Study_, Urban Institute, Washington, D.C.,

various types of service arrangements have been pointed out by Melia (1974), Frieden (1975), and LaVor (1976). The range of existing service models is represented by Brattgard (1971), Stock and Cole (1975), Pagano (1974), and Nugent (1972).

A basic philosophical issue in the provision of housing is the degree to which living arrangements for physically handicapped persons should be integrated into the mainstream of society. This issue is referred to as a process of normalization in the extensive literature on deinstitutionalization for mentally retarded or emotionally handicapped persons (see, for example, Kugel and Wolfensberger, 1969). In general, progress in providing community-based living settings seems to be more advanced for these populations than for the physically handicapped population. The movement to provide halfway houses is discussed by Rausch and Rausch (1968), and detailed studies describing the development of specific community-based programs are exemplified by Fairweather, *et al.* (1969).

Today, there exists a range of housing alternatives for physically handicapped persons that fall at various points on a continuum between social separation and social integration. Separate and specialized alternatives are exemplified by the Het Dorp Village in the Netherlands and by large Housing and Urban Development projects for the elderly and handicapped in the U.S. Integrated programs are exemplified by the Independent Living for the Handicapped program in Brooklyn and by the Center for Independent Living in Berkeley, where a registry is maintained of potential attendants and of accessible apartments throughout the community.

Important dimensions that distinguish one housing alternative from another have been discussed by various writers (see, for example, Fay, 1975; Laurie, 1975). Few studies exist that analyze these dimensions in detail for specific settings, though this type of research has been done in some institutional settings (see, for example, Goffman, 1961, or Miller and Gwynne, 1972). Such studies would be useful in planning the development of new housing alternatives.

Recently, efforts have been made to determine legislative or programmatic changes that would foster the further development of housing opportunities. Examples of written analyses are found in McGuire (1976) and in the White House Conference Awareness Paper on Community and Residential-Based Housing (1975). Concerned action has begun to appear in this field which may lead to the provision of wider choices of life-styles for physically handicapped individuals.

The Project

In Houston, Texas, as in many large cities, there is an increasing need for special living arrangements for the severely handicapped young adult if he is to reach maximum potential. The Texas Institute for Rehabilitation and Research (TIRR), in cooperation with the Houston Housing Authority and the Texas Rehabilitation Commission, began a pilot residential program in January, 1972, especially designed to meet the residential, physical, psycho-social, vocational, and economic needs of this population. The

general purpose of the prototype program was to investigate the feasibility and consequences of a cooperative housing arrangement as an alternative to living with families or in nursing homes. The project was housed in a modern, dormitory-style building which was shared with the Texas Institute for Rehabilitation and Research Annex. The residential section of the annex had a capacity of 18 persons. It was intended that the establishment of such a facility with supportive rehabilitation services, including attendent care and transportation, would offer opportunities for severely physically handicapped persons to live independently and to become vocationally successful and economically self-sufficient. For the most part, the persons in the study group were previously bound to static, non-productive existences because of the lack of physical and economic opportunities.

The grant period of this project was three years; however, the report will focus on four years of reporting since the granting period began six months after the project was initiated. An additional 18 months at the end of the project are reported to enrich the longitudinal perspective on individual resident performance.

The Project's Goals

The initial purpose set forth in this study was the in-depth examination of the requirements for establishing a residential facility for severely physically handicapped, non-retarded, young adults. Examination of the subject prior to the initial grant request reflected that adequate documentation of experience and results in providing residential care to the severely physically handicapped had not been demonstrated in the United States; therefore, in order to establish a body of experiential knowledge, the R & D effort focused on

- determining the requirements for establishing an independent living arrangement for severely physically handicapped young adults and developing a workable model;
- providing new vocational and educational opportunities for the individual;
- determining the feasibility of sharing costs, thereby reducing costs to the individual, his family, or the agencies that support him;
- evaluating the impact of an independent living system on vocational-economic productivity of the individual;
- assessing the changes in attitude and socialization of the individual;
- monitoring improved health practices;
- determining the feasibility of extending this project to a larger population.

Preliminary Planning

Beginning in the 1960's, several attempts to initiate a modified living arrangement for persons with severe physical disabilities were made by personnel at the Texas Institute for Rehabilitation and Research. A suitable facility could not be secured, nor was the necessary agency interest developed. A community-wide conference sponsored by the TIRR and the Community Welfare Planning Association of Greater Houston was held in March, 1968, to explore the feasibility of establishing a special residence for severely handicapped young adults. The need was well documented by the community agencies present, and a recommendation to pursue the project was made. After efforts to mobilize local funding failed, it was concluded that a stop-gap measure was indicated. Therefore, a local nursing home was approached to establish one wing of its facility as a residential setting for severely handicapped persons in nursing homes in Houston. However, evaluation of the results indicated a need for more appropriate plans. Several problems arose in the nursing home project.

(1) The unaccepting attitude of nursing home personnel toward the severely handicapped young adult forced movement of this group from one nursing home to another.

(2) A lack of physical mobility existed in the nursing home because of transportation problems and the absence of an atmosphere geared toward outside involvements of residents. The nursing home resident was generally considered an "ill" person.

(3) There was a penalty for vocational activity. The residents became welfare clients classified as needing intermediate nursing care, and any employment affected continuing welfare eligibility. As a result, attitudes of hopelessness and futility developed. The "what's the use" cycle became a way of life, and a static, non-directed population was the by-product.

(4) Nursing homes were unable to offer a required level of care on a long-term basis because of financial limitations in reimbursement practices.

(5) Nursing homes did not segregate the severely handicapped young adult from the geriatric resident because a nursing home's primary function is to focus its total program (care, food preparation, and social programs) on a geriatric population.

In 1970, a planning and development committee was appointed to make another attempt at developing a special residential program. This committee was composed of several handicapped persons and representatives of the local housing authority, the Texas Institute for Rehabilitation and Research, and the Texas Rehabilitation Commission. In late 1971, TIRR purchased a partially completed facility to house the proposed residential program, which officially opened in January, 1972.

Previous surveys and studies in the Houston area had indicated that approximately 120 persons known to the TIRR wanted and needed a

program of residential services. Since the program only had the capacity to serve 18 persons, the following criteria were established as a basis for selecting the first group of residents.

The residents were to be:

(a) those severely handicapped persons who were bound to a static existence due to limited physical and economic advantages;

(b) those persons who were impeded by inaccessibility of needed health services, psycho-social services, vocational counseling, peer relationships, education, or recreation in their present living situation so that maximum physical, personal or vocational potentials were not achieved;

(c) those persons who had a permanent disability which was thought to be so severe that varying degrees of assistance with functional activities of daily living, e.g., dressing, toileting, eating, transporting, etc., were required;

(d) those persons whose presence in the family was detrimental to the life-style and emotional stability of the family and/or detrimental to the handicapped person himself; and,

(e) those severely handicapped individuals who had the ability to profit either physically, emotionally, socially, or vocationally from an improved environment in which a constellation of rehabilitation services were available in a planned and coordinated manner.

An Environment

Almost every severely disabled young adult has known the desire to live on his own in an environment that gives him a feeling of freedom and independence despite his physical limitations. No matter how strong family resources, most young handicapped people would like to move out of their parents' homes to free not only themselves but their families of the restrictive dependence that is inherent in their individual handicaps.

Unfortunately, a longing for independence is not enough to achieve it. Few severely handicapped, college-age youths can afford to pay for an apartment, a cook, a driver for transportation, and an attendant. For that matter, few apartments are accessible to wheelchairs.

A common, but usually depressing, alternative to getting an apartment is moving into a nursing home. It is understandable that most young adults who do so find themselves hating the situation. The first objection is that it is an institutional, hospital-like environment. There are hours and rules to be observed, and nurses' schedules to be reckoned with. A majority of the nursing home residents are elderly or ill, and this tends to have a demoralizing effect on younger handicapped residents. Even though it may free a person from the dependence on family, life in a nursing home is a far cry from independence.

In the Cooperative Living project, attempts were made to create a new environment which would meet needs and overcome nursing home problems. A major concern in creating this environment was the programming of care and daily activities. The setting required almost all the services of a high-level comprehensive nursing home while avoiding its institutional features. Therefore, there were no designated visiting hours, no bed check, no highly formalized administrative rules. The program was operated without dictating personal behavior. The only requirement was that the individual resident not jeopardize the project or the well-being of other residents.

In former living settings, the residents had little freedom in decision-making. In the Cooperative Living project, each person was individually responsible for his own actions. Undoubtedly, these men and women came closer to achieving maximum independence in the new environment than many of them dreamed possible after becoming disabled. This small but important element in itself is a measure of success.

In a nursing home or home environment that is devoid of resources, the handicapped person has little or no motivation to improve his life-style. In the new residential setting, however, all residents began the process of achieving defined goals. Peer support had many positive consequences, since no environmental limitations were hindering success or goal attainment.

In establishing the ingredients of the Cooperative Living environment, the need for counseling help to enable each resident to cope with his new freedom and responsibilities was evident. Frequently, disability can arrest the growth process as it relates to assuming individual responsibility, carrying out obligations, and exercising newly established emotional freedoms. It is easy to assume that if given an environment of maximum freedoms, the individual will exercise his freedoms and responsibilities wisely. However, this conclusion is based on assumptions that persons will know how to utilize and cope with newly emerging areas of functioning. This is perhaps an overused fallacy. In an effort to achieve maximum functioning for each individual, regular group sessions to deal with reality problems of daily living were led by the project director, a licensed social worker.

PART II: THE PROJECT

Space

In 1971, the Institute acquired a modern, single-story building located in the near-downtown Montrose area which was once an exclusive residential section of Houston. This structure, known as the Annex, is located four miles from the main TIRR building in the Texas Medical Center. It was designed to be used as a respiratory hospital and has a capacity of 36 persons. The building is divided into symmetrical halves with separate hallways. One half was used by the Institute as a nursing station for medical rehabilitation patients. It is referred to in this report as Station 5. The other half housed the Cooperative Living residential project from January of 1972 through September, 1975.

Living in the residential project was like living in a dormitory. Fourteen rooms lined a single hallway with 10 single rooms in the middle and two doubles at each end. Residents shared a common shower room, a recreational room with a television set and pool table, and a dining area. There were also separate rooms for the project attendant staff and for the residential manager's office.

Each resident's room had a single bed, a built-in desk and shelves, a night stand, closet, and wheelchair-accessible sink. Bathrooms with commodes were located between pairs of rooms so that each was shared by two persons. Most residents personalized their private space with bedspreads, posters, wall hangings or plants. Many had stereo equipment, television sets, or small refrigerators. Hardware was designed for persons with limited use of their hands. This permitted a number of residents to be more physically independent than they had been in other living environments.

The spatial arrangement of the project fostered the kind of social closeness that is typical of dormitory settings. When persons first entered the project, they usually enjoyed close contacts with peers who provided support as individuals were leaving their families for the first time. They were also influential models of new kinds of behavior. Many residents felt reassured by the immediate availability of attendants in the common hallway as they first left the care of family members. In time, however, most residents outgrew these needs for closeness and wanted to move to a living space that provided greater privacy for being alone and for entertaining close friends. This developmental pattern is typical in our society as high school and college students frequently outgrow their need for peer group solidarity and develop a desire for greater privacy and more intensive personal relationships.

The physical space in the project provided for a capacity of 18 residents with 10 persons in single rooms and four pairs of roommates in double rooms. Experience soon demonstrated that the system worked much better with 14 residents, using all of the rooms as singles. It seemed important to each individual to have a backstage area where he or she could withdraw for

privacy. Some individuals spent quite a bit of time with their doors closed. Others kept their doors open most of the time, even while studying or resting, in order to monitor activity in the hall and to encourage other residents to wander into their rooms.

When asked for their evaluations of the physical space, most residents suggested several improvements. They generally would have liked larger private rooms with more storage area for supplies, wheelchairs, and other equipment. Many would have preferred low pile carpeting to tile floors, which they felt had an institutional flavor. They also viewed the single long hallway as institutional. Many persons expressed a need for a covered parking area to unload from the project van or from private cars. Almost all residents liked sitting outdoors to socialize and wanted a lawn or garden area (the building had an interior atrium which the residents liked as a design element, but it could only accommodate four or five wheelchairs, which limited social interaction).

Attendant Care

Bringing together a population of 18 severely handicapped young adults required the development of a system of care that would engender feelings of physical and emotional security in each resident, provide for their daily needs, and allow maximum personal freedom. The structured program to render care was intended to be foreign to any traditional nursing care staffing model. To implement this concept, a completely non-professional staff was utilized. The non-professional staff was intended to serve as a positive force in the development of the non-institutional environment.

The initial group of attendants were carefully selected from college students and conscientious objectors who were doing alternate service. Findings have demonstrated that the level of care was good and essentially without medical complications, and that the routine daily care regime can be totally assumed by non-professionals prepared with in-service training. However, the need for some form of professional medical backup is required in a facility of this type for non-routine care requirements. Since the program shared space with an established in-patient service, the need for backup care could be documented.

The primary consideration in developing organizational policies for the residential project was to allow maximum independence and flexibility for each individual in an informal and unstructured atmosphere. Many characteristics of an institutional environment, such as regimented schedules, monitoring of behavior, and restrictions on visitors and on the freedom of residents, were purposely avoided. Operational procedures evolved to coordinate the activities of residents and staff while maintaining flexibility for both.

The staffing pattern at Cooperative Living departed in several ways from that of many institutions. Instead of using a system of regular eight-hour shifts, employees were scheduled according to the activity of residents. The

largest staff was available during peak activity periods, from 6:00 to 10:00 am, and 6:00 to 10:00 pm, and a minimal staff was used at other times. Members of the staff were primarily college students who had no prior medical training. They were taught to perform required services by the residents, who directed their own care. There was no shift supervisor, and staff members planned and organized their work by referring to scheduling lists completed by the residents. No uniforms were worn by the staff since residents felt that this social separation was unnecessary.

The attendant service requirement of each resident was established prior to his entrance. Three categories of attendant care, each representing a cost based on the number of services required by each resident, were established. The following list of services provided a measure of the attendant care needs of each resident:

(a) requires assistance in getting up and getting dressed;

(b) requires assistance in getting undressed and ready for bed;

(c) requires assistance in transferring from bed to wheelchair and vice-versa;

(d) requires assistance in preparing for and taking a shower;

(e) requires assistance in eating;

(f) requires assistance in turning and positioning at night;

(g) requires assistance in getting necessary day rest; and,

(h) requires assistance in transferring to and using a commode chair.

Those residents who required from one to four services were placed in Category 1; those requiring five to six services were in Category 2, and those requiring seven to eight services were in Category 3.

The three-level concept was well accepted by the residents since the more activities they were able to master themselves, the less they had to pay for attendant care. Overall, the residents became more functionally independent as the system was never interpreted as an unreasonable challenge; in most instances, in fact, it was interpreted as an incentive.

The service needs of residents were organized by a system of activity lists. Get-up sheets, evening activities lists, and shower lists were kept in the orderly room, and residents signed up on each of these lists for specific times they wanted services performed. (See Appendix B.) Any conflicting demands were resolved through a system of priorities in which getting ready for school or work took precedence over other activities. It was understood when residents moved in that everyone was expected to consider the needs of others as well as his own, and compromises were sometimes required of everyone.

Transportation System

When the Cooperative Living project opened, residents had to arrange their own transportation to various activities. Within a few months, however, a cooperative transportation system was devised utilizing vans which belonged to several of the residents. A driver was hired by the project, and the owner of each van was reimbursed when other residents were transported in his vehicle. Trips were scheduled using a sign-up sheet and system of priorities similar to those for attendant services. When it became apparent that the operation of this system would be a sizeable financial drain on the project, it was decided to charge each resident a flat fee per month for transportation. Many individuals relied exclusively on this system for transportation to school or work. For those who could drive, it provided a useful back-up system. Later, a second driver was hired to keep up with the needs of the residents. A GMC van that is specially equipped to accommodate persons in wheelchairs was purchased in October, 1973, with a grant from the Texas Rehabilitation Commission.

Food Service

Meals were provided by the food service department of TIRR which had a kitchen in the annex building. Residents ordered food on a meal-by-meal basis, though many chose to order food from outside or to eat out.

Costs of Services

The costs of services in the residential project can be considered by viewing Chart 2:1, Monthly Living Costs in Various Residential Environments. The Cooperative Living Project cost ($570 per month) compares favorably to costs in other environments, specifically a nursing home ($743.00)*, where it is noteworthy that the Cooperative Living alternative is less expensive than traditional institutionalization. The Cooperative Living model as a cost effective system is further highlighted when comparing the Cooperative Living costs to the apartment environment with private attendant. In this arrangement, only 40 hours of attendant services can be purchased for the $320.00 figure suggested to cover attendant assistance, while the $200.00 figure under the Cooperative Living system purchases 24-hour coverage seven days a week.

Chart 2:1
Monthly Living Costs In Various Residential Environments

	Nursing Home	Cooperative Living Project	Apartment With Shared Services	Apartment With Private Attendant
Rent	$	$110	$150	$170
Meals	513	75	100	120
Attendant Assistance		200	220	320
Transportation	100	55	60	100
Personal Needs	130	130	130	130
Total Costs	$743	$570	$660	$840

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*Nursing home costs in Texas, November, 1975.

Problem-Solving

In a flexible system dependent on individual responsibility, there was potential for abuse by both residents and staff. Problems arose on occasion with conflicts between residents and lack of dependability on the part of employees. Meetings of the staff or of residents were called when tensions and difficulties occurred. Originally, resident meetings were scheduled each month to air grievances and discuss needed changes in operating procedure. Later, meetings were called whenever the operation of the system became problematic. This usually occurred at approximate six-month intervals.

For the most part, these general policies and specific operating procedures were very successful in organizing the provision of services and in accommodating the needs and demands of individual residents. The system's greatest strength was its flexibility. Revisions in scheduling occurred each semester, and other changes were readily made when residents felt the system might be improved.

Evolution of a Management System

The system of management in the program was constantly re-evaluated and altered in an effort to find the most effective and responsive approach. The responsibility for the every-day management of the program was first assumed by a resident manager who was charged with the task of handling all staff and resident relations. However, this method did not foster a level of group cohesiveness.

After evaluation of the single manager concept, a manager with a resident council was established. The council, composed of four residents elected by their peers, met as a body with the resident manager. Their functions were defined as follows:

(1) to develop internal programs and operational plans that improve the daily life style of each resident;

(2) to hear problems concerning residents' inter-personal differences and make recommendations for their solution;

(3) to evaluate staff performance along with the resident manager and make recommendations for improvement of care techniques;

(4) to assume responsibility for peer evaluation in terms of accomplishment toward individual goals; and,

(5) to hear complaints of a behavioral nature and make recommendations to the project director if a resident should be asked to leave the program.

The residential council approach functioned well until a power struggle between the residents and the resident manager occurred. At this point, a pure resident council management system evolved. In this system, four residents were elected to serve on the resident council for a term of six

months each. Each council member was paid the equivalent of one-fourth the manager's salary. Being paid to perform certain assigned duties encouraged better management since the council in the resident manager-council system was totally voluntary. The resident council members were required to receive a vote of confidence of their peers or they were replaced.

Specifically, the resident council had the following authority and responsibilities:

Authority:

(a) Council will evaluate residential program, develop policy, and implement procedures;

(b) Council will concern itself with internal problems related to program, including staffing and resident performance; and,

(c) Council members will function co-equally.

Responsibility:

(a) Council will screen, hire, and terminate potential staff members;

(b) Council will evaluate staff performance and determine compensation for attendants;

(c) Council will develop staff policies;

(d) Council will develop a plan of supervisory-staff relations;

(e) Council will maintain a system of accounting and financial record-keeping and report this information periodically to the project director; and,

(f) Council will plan for 24-hour, seven-day attendant coverage and will provide appropriate supervision of the attendant staff.

After analyzing these three management approaches (resident manager, resident manager-council, and resident council), most residents felt that the resident council approach created the most positive group atmosphere and encouraged greater group cohesiveness.

From the viewpoint of the program director, the single manager approach of managment styles was desirable because communication was primarily with one person. However, the council approach seemed to be the most effective for the residents, for it seemed to have the most effect upon the development of the living environment and ecology, the effective utilization of services, and the encouragement of a greater level of cooperation.

In summary, the major factors distinguishing the Cooperative Living residential system from institutional settings are as follows:

(a) the residents were responsible for the daily management of the program;

(b) the residents were actively involved in creating their own living environment and ecology;

(c) the residents utilized broad guidelines to select incoming residents;

(d) the residents and the resident council dealt with all resident behavioral problems and utilized peer action to censure or dismiss residents;

(e) the residents were supported by a system of services designed to foster outside involvement in educational, vocational, and social activities;

(f) the residents exercised self-determination and were responsible for making their own decisions and directing their life-styles; and,

(g) the residents were encouraged by the cooperative system to participate in the mainstream of activity.

The Residents

For a better understanding of the types of persons who entered the Cooperative Living project, brief vignettes on each of the 40 residents can be found in Appendix A. These residents are referred to by case number in many of the charts found in the report.

To summarize the data from these case studies, of the 40 persons who entered the Cooperative Living project from January, 1972, until December, 1975, 31 were male and nine were female. (See Chart 3:1.) Thirty-six were quadriplegics and four were paraplegics. The residents ranged in age from 19 to 33 years, and those with traumatic disabilities had been injured an average of four years and eight months before entering the project. The average age at onset of disability was 18, so most of the residents had not lived away from their parents' homes before becoming disabled.

Chart 3:1
Resident Population

Age At Admission	Quadriplegia (spinal cord injuries)			Quadriplegia (other disabilities)	Paraplegia (other disabilities)
	C4-5	C5-6	C6-7		
18-21	000	●00 00	00	●●	●●
22-24	0	●00 000 00	000	0	●
25-27	00	000	0	00	
29-33		0		●0	●

n = 40

0 = Male
● = Female

At the time of application to the project, 13 persons in the group (six males and seven females) had resided in rural areas where they found few resources such as educational facilities or jobs. Eighteen persons were residing in urban areas (17 males and one female), eight persons had been living in nursing homes (seven males and one female) and one male was in a hospital setting.

Chart 3:2 reflects the level of physical dependency of the residents upon their parents, attendants, or significant others for assistance in meeting their daily living activities. The project admissions criteria required that the resident use a wheelchair for mobility and need attendant assistance for some activities of daily living. For the most part, this group would be classified as severely disabled.

Chart 3:2
Degree of Dependency

	Not A Problem	Problem Managed by Individual	Some Dependence On Others	Complete Dependence On Others
Dressing	1	3	7	29
Grooming	14	13	8	5
Toileting	1	2	10	27
Eating	16	6	17	1
Transferring	5	4	9	22
Transportation	0	5	6	29
Mobility with Wheelchair	19	13	8	0

n = 40

There are many reasons why each member of the group sought to become involved in the residential project. The primary reasons given by the residents are reflected in Chart 3:3. The largest group of residents (35%) gave inadequate resources available in their community as the reason for requiring residential services. This figure correlates with the 13 residents who came from rural areas. Thirty percent of the residents indicated that their family was unable to maintain the demands for providing adequate care. Another group (22.5%) indicated that they were interested in leaving a nursing home since they had been forced into nursing home confinement due to limited family assistance or since other living options did not exist in the community. Some residents indicated that they required residential services since their family members were ill. In several instances the residents were interested in relieving members of the family for other obligations, such as caring for other children or securing employment.

Chart 3:3
Primary Reasons for Requiring Residential Services

Parents ill and/or infirm	3
Family unable to maintain demands for adequate care	12
To relieve member of family for other obligations	2
Inadequate services available in community	14
To get out of nursing home	9

n = 40

Viewing the socio-economic circumstances of the residents at the time of admission, 21 persons (52.5%) were inactive in either employment or educational pursuits. Nineteen persons were engaged in schooling at either the high school, junior college, senior college, or graduate school level. One resident was employed part time at the time he entered the project, but none were employed on a full time basis. The residents were therefore dependent upon multiple sources of income, including social security, welfare assistance, vocational rehabilitation, veterans administration, supplemental security income, parents, or combinations of these sources. Chart 5:2 in Chapter 5 treats in detail the residents' sources of income and changes in use of resources. Considering income from all sources, the mean level of income at admission was $122.59.

In the case of most of the 40 handicapped persons who entered the Cooperative Living project, this experience was the first move away from their home or from an institutional setting. Entering the program meant assuming an adult status for the first time. New responsibilities emerged, such as taking the initiative in getting things done, making decisions, budgeting time and energy, and managing financial affairs. For many persons, Cooperative Living also provided their first chance to develop social relationships and to become involved in outside activities such as school, vocational training, and work.

Members of the Project Social System

The social system of the project was made up primarily of the residents, the attendant staff, and the project driver. Other individuals were peripheral members of the system. Some of these persons saw the residents on a day-to-day basis, but interaction with them was less intensive than that of regular members. Peripheral members included some of the nurses and therapists from the nursing station on the other side of the building, housekeeping and maintenance personnel of the annex building, and the project research director who had an office in the building. A few other individuals interacted frequently with the project as representatives of other organizations. These included the project director, who was a major staff member of the Institute (Director of the Social Work and Outpatient Departments), a courtesy counselor from the Texas Rehabilitation Commission, and a case worker from the Houston Housing Authority.

The group of residents ranged in number from 10 to 18 members who were from 18 to 33 years old. The majority were male, although the project almost always had one to three female residents. In most cases, the women were incorporated into the system as "one of the guys" (residents' term). In one case, a female and male resident had a sexual relationship which lasted for several months. One woman, who was somewhat older than the majority of the residents (age 33), preferred a quieter and more private life-style and did not spend much time socializing with the group as a whole. At the beginning of the project, most residents were from Houston and had been living with their parents and attending the University of Houston. Later, the population included more persons from small towns and more persons who had been inactive before entering the project.

The attendant staff was an important part of the project social system. The staff was made up primarily of students and other persons who were willing to work at the minimum wage. During the first year of operation (1972), several attendants were conscientious objectors doing alternative service. Other attendants were students recruited from college placement offices and individuals from the general labor pool found through the Texas Employment Commission, newspaper ads, and personal contacts. In staffing the project, it was assumed that male residents could have either male or female attendants but that female residents needed female attendants. Males were valued as attendants because they could lift more, and females because they tended to be more reliable and stayed longer.

Interaction Patterns

To a large extent, friendships in the project were based on shared involvement in outside activities. Those residents who were in graduate school, those who were undergraduates at the University of Houston, those who were attending junior college, and those who were in vocational training at the TIRR Work Activities Program tended to interact with other members of these categories. This was probably due in part to similarities in age and in educational level. These categories did not constitute firm lines of social cleavage, however, and a number of friendships crosscut common involvements in outside activities. Two of the residents were black and two were of Mexican-American descent. Ethnic identity seemed to have no impact on interaction of these persons with other residents, though one black resident seemed closer to several black attendants than most residents were.

The degree of group solidarity varied from time to time. As the project began, many residents reported a fraternity *esprit de corps* which became less intensive over time as individual residents became more involved in separate outside activities. From time to time, various residents planned group activities for the express purpose of fostering group solidarity. These included trips to ball games, to the beach, and to restaurants, as well as activities within the project such as barbeques in the atrium or an evening of folksongs. Several projects were arranged by the attendants for the purpose of promoting solidarity. The group was also united from time to time by its occasional conflicts with staff members from the other side of the building. These conflicts most frequently centered on allegations by nursing and maintenance personnel that the residents were too wild and irresponsible in their drinking and loud behavior. The residents in turn felt that their behavior was reasonable and that these staff members were unduly puritanical and did not recognize that the project was their home. The project director usually mediated such conflicts, defending the residents' rights to self-determination of their life-styles, while at the same time urging them to consider the other occupants of the building.

There were several different patterns of interaction between residents and attendants. Some attendants, especially students, became friends of the residents and interacted as peers. Others interacted on a more business-like basis as employees. A few of the attendants liked to wear uniforms to

work, a practice most residents disliked. Some attendants seemed to enjoy the mothering aspects of their work, though in general they did not impose this mode of interaction on persons who resented it.

The residents used two successful styles of interaction in dealing with attendants. The most common style emphasized diplomacy. Persons who followed this pattern felt that it was important to have attendants like them, or at least feel no direct animosity toward them. They considered the attendants' work load in asking for help, and tried to spend their time with attendants in conversation that both enjoyed. Attendants usually liked this mode of interaction and often performed special services that were not requested for diplomatic individuals. Residents who emphasized diplomacy were usually acutely aware of the consequences of alienating attendants and were reluctant to criticize poor work because they felt that the attendants would retaliate by ignoring them in the future.

The second basic style of dealing with attendants was more authoritative. Residents who followed this pattern regarded attendants as employees, and often took no pains to interact with them socially unless the attendant was particularly compatible. Authoritative residents were usually older and more mature individuals who were self-confident and did not fear making attendants angry, for they felt they could deal with any attempted retaliation. Authoritative residents usually received only the assistance they requested directly. Most attendants did not dislike authoritative residents so long as they were "reasonable," but they resented abusive language and other expressions of anger. A few residents seemed to vent a great deal of anger on the attendant staff, primarily through abusive language and other expressions of anger. Frequently this was a way of expressing frustration they had encountered in settings outside the project rather than an expression of displeasure with the attendants themselves. The residents who dealt most successfully with attendants were those who experimented with their own behavior and monitored its effects on the attendants. Such persons often adopted different interaction styles with different attendants.

In addition to these successful styles of interacting with attendants, residents employed several modes of interaction that were unsuccessful and usually prompted the attendants to thwart the residents' wishes. One of these modes was a demanding style of requesting constant assistance. Attendants usually responded to persons who requested help they considered unnecessary by trying to ignore the individual in the future. Attendants would sometimes go to great lengths to avoid passing doorways of such residents because they were always asked to do tasks if they were available. One resident attempted to deal with attendants by constantly threatening them with legal action if they dropped him or made errors. Instead of making the attendants more careful, this behavior often made them so nervous that they could not work well. In response they tried to avoid all interaction with this resident. A final unsuccessful style of interaction used by one resident was ingratiating behavior. This individual

was extremely friendly with attendants, frequently invited them to spend long periods of time in his room, and tried to buy their loyalty with gifts and special favors.

As the project was getting started, the project director, whose office was at the main building, visited the annex frequently to meet with management personnel and with the residents. Later, he became less involved in the day-to-day operation of the project. Every few months he would meet with managerial personnel to review operation of the project. He also was called every few months by residents who wanted to air grievances about the system, and in response to such calls, resident meetings were usually called. In these meetings, the project director sought to guide the residents in devising solutions rather than solving the problems himself. Some residents would participate quite openly in these meetings, but many did not like to air their complaints or feelings before the group as a whole. One reason for this was fear that any complaints they made about attendants would get back to the staff members quickly and they would get less services than before. This fear was probably well-founded.

The research director had an office in the Annex building which was shared with the resident manager, and she consequently had frequent contact with the residents. In some cases this contact was superficial and in others the research director and residents became good friends. A number of residents used this person as a contact broker to expedite relationships with agencies, with the Texas Institute for Rehabilitation and Research, and with other organizations such as the Work Activities Program and the University of Houston. Sometimes the research director was asked to help in solving individual problems and personal issues such as feelings about marriage. Substantial personal problems were referred to the Social Work department of the TIRR.

Contacts with agency personnel developed according to the personality and interest of the agency representative. Interaction with persons from the housing authority or social security office was usually confined to business matters. In contrast, some TRC counselors assigned as courtesy counselors for the project took a great interest in the residents.

Roles

Among the group of residents a number of roles developed. One of these was the role of "contact broker," a term borrowed from Eric Wolf's (1956) concept of the culture broker, whom he defines as a person who facilitates contacts between a local and larger-scale social system. The project contact broker was always an individual who had an extensive social network and who could tell other residents who to contact to solve specific problems and to request favors. The broker's network of contacts might include agency personnel who could unsnarl bureaucratic red tape, persons who had knowledge about part-time jobs, or persons who could provide introductions to potential new friends. Contact brokers in the project were individuals with social competence who served as behavior models for other residents as

well as supplying them with useful information. There were four persons who filled this role at various times. Some brokers were also found in the four apartment clusters developed as outgrowths of the Cooperative Living effort. They were found in some nursing homes with young persons but not all such nursing homes. Handicapped persons who were isolated without anyone to serve the brokering function were at a great disadvantage in trying to be active and get things done.

A second role that emerged in the project was that of "goat." With very few exceptions, there was always one individual in the project, and sometimes two persons, who demanded more assistance from attendants than the other residents felt he needed and who was thus defined by the group as a problem. (This role was always occupied by males.) The other residents all expressed irritation at this behavior and often put a great deal of pressure on the individual to do more for himself and to organize tasks so that attendants' time could be used more efficiently. This social pressure never had more than a very temporary effect on the behavior of the goat, though the individual in this role would sometimes be less demanding for a few days after the resident management council asked him to modify his behavior. The residents felt that this demanding behavior pattern resulted from the individual having been "spoiled" by too much care from family members at home. The individual was probably asking for social closeness from the attendants rather than for the physical help he said was needed. Irritation at such behavior was a frequent topic of conversation among other residents, which served as a strong sanction supporting the value of maximizing independence that pervaded the project.

A third role was that of "cruise director," who arranged social activities for the entire group. This role was played from time to time by various individuals, but was most enthusiastically pursued by one particular resident over an eight-month period. This individual had come to the project wanting a vocational evaluation and rapid job placement, but because of his severe disability, a job was not found. He used much of his enthusiasm for being active and exercising his control by organizing social activities. Some months later, when he started junior college, his interest in the role of cruise director dwindled. Almost all of the residents enjoyed taking part in these activities, though few other residents ever helped the cruise director to organize them despite his requests for help with this task.

An additional role was that of "recluse," which five residents chose during the course of the project. In two cases, the recluses' families lived within 100 miles of the project, and these residents went home most weekends while keeping to themselves during most of the week. In all but one case, this choice of minimal involvement in the social system was accepted without resentment by other residents. One recluse was viewed negatively by the other residents because they considered his behavior an expression of intellectual snobbery. Four of the recluses were somewhat older than the majority of residents at the time they left the project. The one younger recluse spent a great deal of time studying.

A final role which was more formally defined than the others was that of "manager." This role was filled initially by one person and later by five individuals who served at various times on the resident management council discussed previously. The other residents often felt that the managers received better attendant service from the staff because of their status. Some managers deliberately used their positions as a means of getting privileges. For example, the driver might agree to wait longer for them than he would wait for other residents.

Modeling

In the project, modeling was an extremely important factor in the developmental process of individual residents. Through this mechanism, persons learned new ways of managing their care routines such as bowel programs or skin care. They learned new physical capabilities such as ways of dialing the telephone or getting a pitcher of water. One quadriplegic resident without triceps learned to transfer by observing another resident. Several residents changed their assistive equipment because they had observed other residents use a simpler hand orthosis which could be put on without assistance. Two residents went from electric to manual wheelchairs while in the project. Several residents began part time jobs as a result of seeing friends work part time. Many learned new social interaction skills by observing fellow residents interact with agency personnel, with prospective employers, with prospective attendants, or with potential dating partners. Modeling was important in providing both the motivation and the know-how for experimenting with new behavior patterns and new equipment. Residents also adopted other behavior patterns from each other which had less adaptive relevance, such as an interest in stereo equipment.

Outside Social Contacts

Aside from their primary activities of attending school, vocational training, or work, the residents had a variety of contacts outside their group social system. They visited a number of locations that were within wheelchair rolling range of the project. The locations they rolled to included a bar about eight blocks away, a gay bar across the street, a convenience grocery store about two blocks away, a rather dilapidated restaurant one block away, occasionally a junk shop two blocks away, and occasionally an old building across the street that was used as a practice room by a rock band. Some residents developed friendships through these contacts, though usually personal interaction with persons living in the neighborhood was minimal.

Most residents invited relatively few guests to visit them in the project. Persons originally from Houston tended to have more guests, usually acquaintances they had met before moving in. There were some exceptions, including one graduate student who occasionally invited fellow students over. Residents reported that they met few people in class at the University of Houston that they continued to keep up with once the semester ended. (Disabled persons who lived in the dormitory at the University of Houston also reported that they had initiated very few lasting friendships as a result of meeting people in classes.) A few residents established sexual

relationships with outsiders while living in the project, but the dormitory atmosphere, with little privacy, was not conducive to the development of such relationships. One resident reported that having a sexual relationship was easier in the nursing home where he came from because the young people there had an unspoken rule that they would not pry into such areas. In contrast, residents of the annex expressed great interest in any sexual encounters other residents had. While living in the project, two residents were generally known to have had sexual encounters there. A few other residents had girlfriends or boyfriends visit them, but did not conduct sexual relationships at the project.

For most residents in the project, the internal social system was their primary source of friends. Of those who maintained contact with a number of persons outside the project, almost all were from Houston originally. Predictably, the four clusters located in apartment settings are much more conducive to integration of the residents with an able-bodied population.

Values

Perhaps the most pervasive value held by the group of residents was the expectation that individuals would be as independent as possible. Residents were very intolerant of persons who asked attendants to do tasks they could do themselves, who did not accumulate tasks and schedule requests in order to use attendants' time efficiently, and who expected fellow residents to take care of responsibilities for them such as completing registration procedures at school.

Many of the residents lived a similar life-style. Those who followed this pattern attended school but did not work too hard, were interested in sports, in rock music, in drinking, and in developing relationships with persons of the opposite sex. Some forms of deviance from this pattern were tolerated and even admired, such as a strong commitment to academic work or to religious values. The few individuals who abused medications and were suspected of using other drugs were viewed with intolerance, though several residents smoked marijuana away from the project, which was considered acceptable. The group as a whole sometimes expressed skepticism about new residents who appeared older than the majority, though one older resident was well accepted by the group.

Activity Patterns

Most residents got up and dressed in the morning between 6:00 and 9:00 and were ready to leave in the van for school or work by 8:00 or 9:00 a.m. The van made several trips each day to transport persons to a junior college, the University of Houston, a vocational training project sponsored by TIRR, or to work. During the middle of the day the project area was largely empty. Residents began returning at 3:00 or 4:00 in the afternoon and usually had dinner about 5:30. During some periods the residents tended to eat dinner as a group in the dining room. At other times, they tended to eat alone or with one or two friends, often in individual rooms. In the evenings some residents studied in their rooms. Many spent their evenings socializing in individual rooms, in the recreation room, or hallway.

During the summer, they often congregated on the sidewalk outside the building. On weekend evenings residents frequently visited several bars that were within rolling distance of the project.

Residents took various kinds of trips in the project van to outside recreational activities. The frequency of these trips depended on the interest of residents and on the availability of funds to pay a night driver. These trips included outings for the group as a whole to ball games, restaurants, or concerts. They also included spontaneously organized trips by three or four residents to bars or nightclubs. Residents who owned their own vans (eight of the 40 residents) often got friends to drive them to various activities.

In general, the residents were more active in the project than they had been in their previous living environments, though in some cases this was not true. Most persons enjoyed the opportunity to plan and initiate their own activities without having to depend on the availability of family members or friends for assistance. However, there still were constraints on the activities they could undertake, based mainly on the availability of attendants to accompany them and on the availability of the van and driver. Such constraints are built into any system of shared services in which the needs of more than one disabled person must be accommodated by the system. The greatest compensating advantage of such a system is the cost-effectiveness of providing 24-hour coverage.

PART III: THE RESEARCH

Chapter 4: *Research Methodology*
- Longitudinal Study
- Comparative Study

Chapter 5: *Results and Findings: Longitudinal Study*
- Economic Status
- Activities
- Mobility Patterns
- Living Arrangements
- Attitudes
- Medical Status

Chapter 6: *Results and Findings: Comparative Study*
- Cooperative Living Project
- Moody Towers Dormitory
- Nursing Homes
- Apartment Clusters

Chapter 4: *Research Methodology*

Two main types of research have been conducted on the Cooperative Living project to monitor changes in the lives of residents and to compare this living environment with other residential settings for severely physically handicapped young adults. The first of these is a longitudinal study in which data were collected using standardized interviews before individuals entered the project, during their stay, and after they moved on to other living environments. This study was intended to assess changes in residents' life-styles in the areas of physical independence, medical status, educational or vocational activities, leisure activities, social relationships and patterns of interaction, economic status, and attitudes.

The second type of research was an anthropological study comparing the Cooperative Living residential environment to other living environments for disabled persons in Houston. The environments studied included, in addition to the Cooperative Living project, a dormitory at the University of Houston, several nursing homes, and the four apartment clusters in Houston offering shared attendant and transportation services that developed as outgrowths of the Cooperative Living project. This comparative study was supplemented by two discrete research projects that compared the group of Cooperative Living residents with groups of similar persons living in nursing homes.

Both of these studies are described below. The results of the research are discussed in Chapters 5 and 6.

A Longitudinal Study of Resident's Life-styles

In this research, data were gathered from all 40 residents before they entered the project, during their stay, and after they moved in order to track potential changes in a number of areas. Information was collected during the three-year life of the project grant, and also for seven months beyond this period to provide a follow-up perspective. The interview schedule for this research is included in Appendix D. Some of the questions dealt with very specific quantifiable information. Many, however, were intended to evoke open-ended discussion of how the residents perceived themselves and their life-styles. Information gathered through interviews was supplemented by a review of each person's medical record and by an ongoing log of medical problems that occurred during the period he or she lived in the project. Residents also were asked from time to time to keep logs of their financial expenditures over 30-day periods. One set of 14 residents were given standardized tests to measure their attitudes in April of 1974. These were followed one year later by subsequent testing with the same measures after those individuals had moved away from the Cooperative Living setting.

A few residents also participated in a sample study of critical incidents that occurred from the onset of their disability to the time of the research interview. This study provided very detailed information on the time

sequence of events considered important by the respondents. It enabled the researchers to view the longitudinal information from the Cooperative Living project in a longer range perspective, since many residents had become disabled several years before entering the project and had already undergone a number of important experiences and changes. This longitudinal research documented changes in the lives of residents which are discussed in detail in Chapter 4.

An Anthropological Study Comparing Residential Environments in Houston for Severely Physically Handicapped Young Adults

In the anthropological research conducted on the Cooperative Living project and other residences, the unit of focus was the environment itself rather than individual residents. The dimensions investigated in each setting included:

a. characteristics of the residence as a physical structure;

b. the location of the residence in relation to other elements of the surrounding community;

c. demographic characteristics of the resident population and types of disabilities represented;

d. the social system of the residence;

e. the outside activities and social relationships of residents;

f. the supportive services provided;

g. the managerial structure and procedures; and,

h. the costs and methods of financing.

Data were collected through intensive interviews with disabled residents and with other members of the social system as well as through direct observations in each environment. Background information about each residence was obtained from administrative personnel.

The settings that were compared included the Cooperative Living project (14 residents), Moody Towers dormitory at the University of Houston (13 residents), six nursing homes (1, 2, 2, 3, 6, and 9 residents), and four apartment clusters offering shared attendant and transportation services (20, 11, 18, and 10 residents). Comparative ethnographies were written on each setting which are based on the analytic dimensions previously cited.

Comparative studies of alternative living environments were supplemented by two separate research projects designed to compare residents of two settings on the basis of activity patterns in one case and attitudes in the other. The first of these two separate studies was a doctoral dissertation that compared 12 Cooperative Living residents, 12 similarly disabled students from the University of Houston who lived in nursing homes or homes, and 12

able-bodied students (Kirksey, 1974). The individuals in each sample were matched on the basis of age, marital status, sex, race, educational level, level of disability, and age at onset of disability. All were students at the University of Houston. Diaries kept by each respondent for a period of one week were used to compare the group on the basis of number and kind of activities, number of settings entered, and number and type of persons with whom interaction occurred. It was expected that by using a matched sample design and thus factoring out variables based on personal characteristics, the study would demonstrate differences in activity patterns that could be attributed to the effects of living in different environments. Actually, the differences in activity patterns between groups were found to be minimal. In choosing a sample of severely disabled persons who were attending school, the investigator selected a group of persons who were atypical of the young disabled population generally and who probably would have managed to lead active life-styles in almost any residential environment.

The second discrete research project was a study of self-concept and attitudes comparing 14 Cooperative Living residents with 14 similarly disabled nursing home residents who lived in four separate homes (Tekell, 1974). Attitudes were documented by the Rotter Locus of Control Test, the Tennessee Self-Concept Scale, and several questions dealing with attitudes that were part of a regular interview format used in longitudinal research on the project (see Appendix D). In general, the two standardized measures failed to reflect differences between Cooperative Living and nursing home residents which seemed to be significant based on open-ended interview questions.

In general, research efforts on the Cooperative Living project were intended (a) to document changes in the life-styles of individual residents of this specific project, and (b) to make more general structured comparisons of alternative living environments for severely disabled persons that permit some assessment of the effects of the differing environments on the behavior and attitudes of residents. The goal was not to offer irrefutable proof of causal relationships. Instead, the purpose was to identify and explore variables which seemed to be important to the residents themselves and which are therefore important to persons who can influence the ways in which living environments are structured in the future.

A number of important changes occurred in the life-styles of the 40 Cooperative Living residents from the time they entered the project until December of 1975. These are summarized below as findings of the longitudinal research conducted on the project. An epilog at the conclusion of the report adds to the time perspective in which individual changes are viewed.

Economic Status

The Cooperative Living project had significant impact upon the residents' economic status, benefited agencies involved in the rehabilitation effort because residents became more self-sufficient, and was less costly as a model of long term care than institutionalization.

Chart 5:1 compares the level of resident income before admission to the project with income levels as of January, 1977.

Chart 5:1
Comparison of Monthly Income Levels

Monthly Income Before Admission Into Project		Current Monthly Income 1/77		
$ 0 – 50	13	$ 0 – 50	1	
50 – 100	8	50 – 100	1	
100 – 150	4	100 – 150	3	
150 – 200	8	150 – 200	7	
200 – 250	4	200 – 250	3	
250 – 300	0	250 – 300	2	
300 – 350	0	300 – 350	1	
350 – 400	2	350 – 400	2	
400 – 450	1	400 – 450	0	
over 450	0	450 – 500	2	
		500 – 600	2	
		600 – 700	3	
		700 – 800	1	
		800 – 900	1	
		900 – 1000	3	
	n = 40	over 1000	4	n = 36*

*An n of 36 is a result of a follow-up study conducted in January of 1977. Of the original 40 residents, one had died, and 3 were lost to follow-up. (See eiplog)

Before admission to the project, 21 persons, or 53% of the population, had an income of less than $100 monthly. As of January, 1977, however, only two persons, or 5%, had an income of less than $100 per month. The mean

income level at entrance into the project was $122.59,* while this level increased as of 1/77 to $496.91. This variation in mean income demonstrates that the project did have an impact upon economic status, and it also indicates that the improvement in status was not temporary.

At the end of the reporting period, December of 1975, the income level of each individual showed an increase due to changes in employment status and sources of subsidy, as illustrated by Chart 5:2.

Chart 5:2
Residents' Sources of Income

	Pre-admission	In-residence	12/75
EARNINGS			
Part time	1	12	4
Full time	0	6	14
SOCIAL SECURITY	17	16	12
SUPPLEMENTAL SECURITY INCOME	4	21	13
STATE VOCATIONAL REHABILITATION	15	32	16
HOUSING AUTHORITY	0	28	0
VETERAN'S ADMINISTRATION	1	1	1
STATE WELFARE	16	0	11
PARENTS	28	4	6
SPOUSE	0	0	5
OTHER (Investments, etc.)	3	3	2

The most significant change in sources of income is found in the earnings category. One person was employed at the time of admission, and at the end of the reporting period 14 persons were employed full time and four part time. Before admission, 28 persons relied heavily on their parents for financial support, while in the project four persons did so. Five former residents were employed and shared the burden of household expenses with their spouses. The support and involvement of the Texas Rehabilitation Commission is indicated by the fact that 32 persons received payments (beyond college tuition) while in the project. Supplemental Security Income

*Mean derived from raw data on income at admission and is calculated on n= 39 rather than of 40 since one resident had above average income from VA disability.

as a support program began during the project in January of 1975, and 21 residents became eligible for this resource while in residence. Only 13 former residents continue to use this resource today, which reflects movement toward economic independence. The process of attaining economic independence is a gradual one as vocational and educational goals are achieved. Given the required environmental supports, individual progression toward personal goals can lead to termination of agency services and assumption by the resident of his own support.

Chart 5:3, Level of Income of 14 Residents Employed Full Time as of 12/75, reflects this shift toward economic independence. The income level of these 14 residents at admission was $1447 annually, or $129.99 monthly. At the end of the reporting period, the annual mean income of these persons was $7560 ($630.00 monthly), a percentage increase of 488%. It is particularly significant that three persons who were confined to nursing homes at the time of admission to Cooperative Living are now employed full time. The shift of these 14 individuals away from agency dependency is reflected by their sources of income before admission. In each case, the agency resources used previously are no longer utilized by the resident since employment earnings are either sufficient to meet required needs or earnings are at a level which results in the resident being ineligible for agency support.

Chart 5:3

Level of Income of Fourteen Residents
Employed Full Time as of 12/75

CASE NO.	ANNUAL INCOME BEFORE ADMISSION	SOURCES OF INCOME BEFORE ADMISSION	ANNUAL EARNINGS 12/75
1	$1440 + vendor pmts.	APTD	$8,400.00
2	$1,136.40	Soc. Sec.	8,400.00
5	1,800.00	TRC Soc. Sec. Family DPW	10,000.00
6	1,300.00	APTD	6,000.00
7	1,598.60	Soc. Sec.	6,000.00
8	1,300.00	APTD	6,000.00
10	1,300.00	Soc. Sec.	10,500.00
11	3,990.00	Soc. Sec. APTD TRC	12,000.00
17	1440 + vendor pmts.	APTD	6,600.00
26	2,535.00	Soc. Sec. SSI	5,400.00
32	2,882.00	TRC Soc. Sec. APTD	10,000.00
33	1440 + vendor pmts.	APTD	7,200.00
36	—0—	Family	5,140.00
37	1,261.00	SSI	4,200.00
MEAN INCOME	$1,557.00 ($129.00 monthly)		$ 7,560.00 ($ 630.00 monthly)

The movement toward vocational and educational activity and productivity has been in part the result of having required services available. Bridging the gap from economic dependence to economic independence was accomplished through a concept of shared services. A severely handicapped person usually requires some assistance with meal preparation, transportation, and personal needs. An environment in which he or she can be physically mobile is also required. All of these requirements must be coordinated and the system must be affordable to the resident and the agencies that support him. The Cooperative Living system was conceived as a way to deal with the long term care costs for a severely handicapped person, yet provide a suitable environment that would foster his potentials. The range of long term care costs is very wide. The service costs may be low if the person lives with parents or spouse; however, daily care in an acute care hospital when a suitable alternative is not available in the community can cost from $200 upward. When nursing home care is the only alternative, the range is from $15 to $75 daily.*

Chart 5:4 compares costs in various residential environments. Nursing home costs in Texas average approximately $724 monthly, or $25 daily, in comparison with Cooperative Living costs of $570 monthly, or $19 daily. The costs for other residential alternatives are also shown. Providing a cooperative living arrangement in an apartment complex has averaged approximately $660 monthly, still less than nursing home placement. Finally, an apartment with private attendants is estimated at a conservative cost of $840 monthly. The actual cost clearly depends upon the amount of attendant assistance needed. Providing 24-hour a day coverage with private attendants is prohibitively expensive for most persons. For the severely handicapped person with an average income, a cooperative system of services, as provided in the Cooperative Living project, appears to be the most economically feasible means of purchasing daily services. The same system of sharing services has also proved feasible and cost-effective in four apartment clusters in Houston.

Chart 5:4
Monthly Living Costs in Various Residential Environments

	Nursing Home	Cooperative Living Project	Apartment With Shared Services	Apartment With Private Services
Rent	$ ↑	$110	$150	$170
Meals	513	75	100	120
Attendant Assistance	↓	200	220	320
Transportation	100	55	60	100
Personal Needs	130	130	130	130
TOTAL COSTS	$743	$570	$660	$840

*Costs based on averages in Houston area.

Charts 5:5 and 5:6 are examples of two residents in the Cooperative Living system. Chart 5:5 illustrates the situation of a civil engineer who began his first job earning $520 per month. Of the options available to him as of 11/73, the only one which was economically feasible was the Cooperative Living project. If he chose the housing alternative of a private home with an attendant, his income would be inadequate to meet his recurrent expenses. The consequences of having to choose a nursing home as a living option is counter-productive for persons who wish to be employed. Current Medicaid programming serves as a disincentive for persons who seek to live in a nursing home and work since there is a dollar-for-dollar reduction in benefits. In this case example, the probable effect of choosing nursing home placement would be a total loss of income as well as the increased cost of care maintenance. Projecting these costs over 20 years, the economic consequences are enormous. The total consequences of income and loss as well as care maintenance are $257,520 for 20 years, assuming that costs remain at 1973 levels. The total cost per case of institutional maintenance alone using fixed costs is approximately $132,720 over 20 years. These figures correspond roughly to calculations of the long-term costs of spinal cord injury made by Young (1972).

Chart 5:5
Comparative Costs of Housing Alternatives Projected Over 20 Years

Case Study: 29 year old severely handicapped engineer who earns $520 per month

MONTHLY COSTS	20 YEARS COSTS
COOPERATIVE SELF-SUPPORT SYSTEM	
$520 monthly income -480 cost of maintenance $ 40 *excess* per month	$ 9,600 *excess* in 20 years
PRIVATE HOME WITH ATTENDANT	
$800 cost of maintenance -520 monthly income $280 deficit per month	$ 67,200 *deficit* in 20 years
NURSING HOME	
$533 cost of maintenance +520 deficit per month	$257,520 economic consequences of institutionalization for 20 years
$1073 total cost per month of institutionalization	$132,720 institutional maintenance cost

Chart 5:6 describes similar consequences of various alternatives over 20 years. As this young computer operator began her first job, she earned $380 monthly. This entry level employment was inadequate to meet the cost of even the Cooperative Living alternative. In instances such as hers, agency benefits, including vocational rehabilitation, SSI, and SSDI, are usually terminated due to earnings levels. A way of bridging the gap with agency resources from entry level employment to employment with increased earnings must be found in order to avoid the consequences of forcing severely disabled persons into a nursing home alternative, therefore causing income loss as well as the add-on cost of institutional maintenance. Plans of self-support written by vocational rehabilitation counselors have allowed individuals to continue receiving some benefits for 18 months after beginning employment. This mechanism is a partial solution to the problem of making a gradual transition to economic self-sufficiency, but it does not adequately deal with other disincentives to employment built into the system, such as the loss of medical coverage at the end of the 18-month period.

Chart 5:6
Comparative Costs of Housing Alternatives Projected Over 20 Years

Case Study: 20 year old severely handicapped computer operator who earns $380 per month

MONTHLY COSTS	20 YEARS COSTS
COOPERATIVE SELF-SUPPORT SYSTEM	
$480 cost of maintenance -380 monthly earned income $100 deficit per month	$ 24,000 deficit over 20 years
PRIVATE HOME WITH ATTENDANT	
$800 cost of maintenance -380 monthly earned income $420 deficit per month	$100,800 deficit over 20 years
NURSING HOME	
$533 cost of maintenance +380 income lost $933 total cost per month of institutionalization	$223,920 economic consequences of institutionalization for 20 years $132,720 institutional maintenance cost

12/73

Activities

From the conception of the Cooperative Living project, it was expected that the program would have a major impact upon the vocational and

educational choices and productivity of the residents. Before entering the project, residents had been faced with obstacles in reaching vocational and educational goals due to lack of transportation, undependable attendant service, and limitations in family resources to provide necessary care and other support services. Many residents were living in environments that were not supportive of their goals. In a number of cases, individuals from rural areas had no opportunities for educational or vocational involvement in their communities. The Cooperative Living system focused on these obstacles and provided a dependable transportation system, necessary physical care services and support at an affordable level, and fostered an environment that encouraged individual resident productivity at a level compatible with the resident's own capabilities.

Chart 5:7 summarizes the vocational and educational consequences of the project. Comparisons are made between the residents' activities on entrance into the Cooperative Living program and their activities as of December, 1975, the closing date of the program. The most significant finding is that 21 residents were classified as inactive (not involved in educational or vocational activities) as they entered the program, and in December, 1975, only three persons were listed as being inactive. Of these three persons, one was working full time during the residence period and one was in college. At the close of the project, however, two of the three were forced into an inactive status due to medical problems, and one became inactive due to family problems that required her involvement.

A second finding is the impact the program had on residents' employment status. At admission into the program, none of the residents were employed, while participation in the project enabled 14 (28.6%) persons to begin working. A number of residents also became involved in vocational training, junior college, college and graduate school for the first time, which should permit their eventual entry into employment.

Chart 5:7
Activities of Residents

	Inactive	High School	Vocational Training	Junior College	College	Graduate School	Full-time Employment
Activity at Admission	●●●●●● ●●●000 000000 000	00		00	000000 000000 00	0	
Status 12/75	●00		●0	●●0000	000000 000000 ●	000	●●●●●● 000000 00

● - Female
0 - Male

N= 40 (N of 41 is reflected under current status since one resident was employed full-time and also in college; therefore she was recorded twice)

Chart 5:8 reflects the variety of jobs secured by the residents. One interesting process was set in motion as residents became successful in finding employment. The success encountered by one resident became the necessary encouragement and motivation for another. It is also important that many residents moved through a process of part-time to full-time employment. During one period in the project, 13 persons were involved in part-time employment. Overall, 22 individuals have had full or part-time jobs.

Chart 5:8
Jobs Held by Residents as of 12/75

PART TIME	FULL TIME
1 – Receptionist	2 – Receptionists
	1 – Research Supervisor
3 – Apartment Managers	1 – Telephone Operator
	1 – College Teacher
	1 – Apartment Manager
	1 – Social Worker (Masters degree)
	1 – Microfilming Technician
	1 – Residential Project Manager
	1 – Sales Representative
	1 – Employment Counselor
	1 – Accountant
	1 – Secretary
	1 – Civil Engineer
n = 4	n = 14

The amount of time required by the residents to secure their first jobs ranged in length from one to 42 months. The residents who represent the longer times were involved in educational or vocational pursuits which had to be completed before obtaining a job. The mean time required was ten months. This suggests that actual job placement is a time-consuming process, but not as lengthy a process as one might assume. Those residents whose job placement process was not affected by the need to complete vocational training or education had a mean time of four months.

Chart 5:9 reflects changes in educational levels of the residents from the time they entered the project to December, 1975. For a more detailed breakdown of specific residents in terms of disability, admission to facility and time in facility, please consult the case vignettes in Appendix A which correspond with cases listed in this chart. During the reporting period, 30 residents participated in educational activities at a high school, junior college, college, or graduate school level. It is difficult to draw any significant conclusions from this data since the individual resident's time in the project varied, and some residents required fewer years to graduation. Those persons in educational tracks were moving toward their goal at a rate of approximately three-fourths of the normal academic load of an

Chart 5:9

Changes in Educational Level from Admission to 12/75

CASE NUMBER	EDUCATIONAL LEVEL AT ADMISSION	EDUCATIONAL LEVEL 12/75
1	15+ years	16 years
2	15+	15+
3	14+	17+
4	13	15
5	14+	16
6	15	16
7	12	12+
8	12	13
9	14	15
10	16	19
11	15	16+
12	12+	12+
13	12	13
14	11+	13+
15	16	18
16	13	15
17	8	8
18	13	13
19	13	15
20	12	14
21	12	13
22	13	13+
23	12	12+
24	12	12
25	12	12+
26	12	12
27	11+	12+
28	19+	19+
29	13+	14
30	12+	13
31	12	12+
32	15	18
33	15	16
34	13	14
35	12	13
36	12	12
37	12	12
38	14+	14+
39	12	12
40	12	12+

For period of time in residence, see vignettes

able-bodied student. During the total reporting period, from January, 1972, to December, 1975, five residents entered graduate school, one finished graduate school, three completed vocational training, and seven completed requirements for a bachelor's degree.

Mobility Patterns

It was expected that when residents moved into the Cooperative Living project, they would be significantly more mobile than had been the case in their former living environments. This was particularly true for persons who had lived in rural homes or nursing homes before entering the project. In these environments, there were frequently no opportunities for involvement in education or vocational training. Moving to Cooperative Living thus meant a new mobility pattern for many persons who previously had not had routine daily obligations outside their homes. It is important to note, however, that many of these persons from rural homes had been accustomed to going out on weekends in their hometowns for social activities with friends who came by to pick them up. In some cases, the individual's number of social outings decreased in the project because evening and weekend transportation was not as readily available as it had been in their home towns. Among the residents from urban homes, a number of persons were already attending college at the time they entered the project. The number of outings for these persons thus did not change significantly with their entrance into the project.

As persons entered Cooperative Living, most of them were incorporated into the established activity and mobility patterns, both within the project and in the surrounding neighborhood. Locations in the area that were regularly visited by wheelchair are discussed in Chapter 3.

Patterns of use of the shared transportation service varied considerably from one resident to another. Distances traveled by 13 persons during a test month were 0, 35, 37.5, 44.5, 49.5, 71, 78, 81, 98, 119, 135, 153, and 247 miles for a mean distance of 86 miles. The individual who did not use the van at all during the test month was confined to bed because of a skin breakdown. The other extreme distance of 247 miles was traveled by an individual who rode to his employment location on a daily basis. This mobility pattern contrasted to that of many persons attending school who arranged their schedule of courses to fall on three rather than five days a week.

Residents used several kinds of transportation at Cooperative Living in addition to their own wheelchairs and the shared transportation service. Ten of the 40 residents owned small vans (usually VW vans) that they kept with them at the project. (Two other residents owned vans that they left at home.) These persons frequently asked friends or off-duty attendants to drive them to social occasions or on shopping trips. This was usually done on a friendship basis, though sometimes persons were paid to drive residents' vans.

Six persons owned sedans during the time they lived in the project. Four of these individuals could transfer and load their wheelchairs alone, and two

required assistance. Two of the four independent persons used their cars regularly to drive to school. The other two chose to use the shared transportation service for this purpose because they wanted to conserve energy for pushing their wheelchairs around campus, or because they wanted to take electric wheelchairs to school. The cases illustrate the important interdependence between electric or manual wheelchairs, transportation vehicles available, and distances to be covered by a physically handicapped person. One C-6,7 quadriplegic, for example, felt it was most adaptive for him to drive his own car to his part-time job where pushing distances were minimal, yet ride in the project van to the University of Houston where pushing around campus was tiring.

Mobility patterns of the Cooperative Living residents in relation to their activities and social contacts were the subject of a doctoral dissertation by Kirksey (1973). The author compared the Cooperative Living population with a matched sample of 12 other handicapped students from the University of Houston living at home or in nursing homes and with a control group of non-handicapped students. Diaries of a week's duration were kept and then coded in terms of types of activities and types of social contacts. Significant differences between these groups in terms of the 15 variables investigated are noted in Chart 5:10. These differences were less pronounced than expected. In choosing a sample of severely disabled persons who were attending school, the investigator may have chosen a group of persons who were atypical of the young disabled population generally, and who probably would have managed to lead active life-styles in almost any residential environment.

Chart 5:10

Summary of Data from a Study of Resident's Social Activities

	Cooperative Living	Home or Nursing Home	Non-Disabled
Number of activities	81.6	82.0	93.1
Number of types of activities	19.0	16.1[a]	21.2
Number of activities carried out with others	51.1[b]	43.3	40.9
Number of activities carried out alone	30.2[b]	38.5	53.8
Number of interactions with people	87.8	71.0	64.4
Number of interactions with people other than family or attendants	67.2[c]	30.8	47.8
Number of different people interacted with	26.1[c]	13.8	23.0
Number of varieties of people interacted with	4.2	3.2	3.5
Number of entrances into locations	15.3	18.3	41.8[d]
Number of different locations entered	7.8	6.7	14.9[d]
Number of types of locations entered	5.8	5.3	9.4[d]
Number of entrances into locations outside residence	8.9	11.5	27.1[d]
Number of vocational-educational activities	8.6	8.7	16.6[d]
Number of social-recreational activities	7.0	4.4	9.6[d]
Number of business-commercial activities	2.3	2.2	4.7

[a] Home-Nursing home group significantly different from non-disabled group
[b] Cooperative Living group significantly different from non-disabled group
[c] Cooperative Living group significantly different from Home-Nursing home group
[d] Non-disabled group significantly different from Cooperative Living and Home-Nursing home group

After leaving Cooperative Living, many of the residents continued to use transportation arrangements they first began to utilize as they developed new mobility patterns at the project. This is true of the 26 persons who moved to apartment clusters that offer shared transportation services based on the Cooperative Living model. A number of individuals also continued to drive their own cars to school or work.

A few individuals developed entirely new mobility patterns after leaving Cooperative Living. For example, one quadriplegic individual purchased a larger van to replace his old VW bus because it can be driven from a wheelchair by his paraplegic roommate. Another quadriplegic individual purchased a van that he can drive himself from his wheelchair after developing major medical problems. His physician advised that transferring himself and loading his wheelchair into a sedan had become too great a strain in light of his changed medical status.

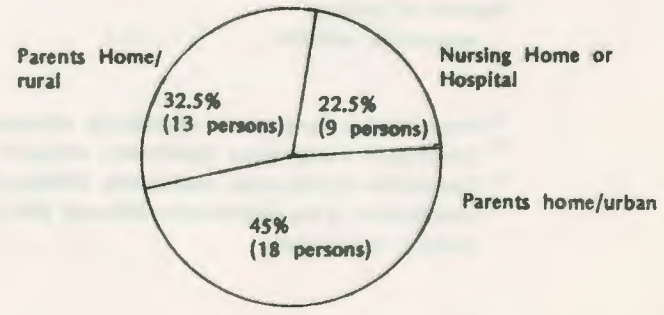
Mobility patterns for handicapped individuals, as for all persons, must be viewed as part of a complex whole that involves activities, place of residence, and numerous other variables. An awareness of possible options and of limiting factors in this area is particularly important for severely handicapped persons. At Cooperative Living, many individuals had an opportunity to test the limits of travel by wheelchair and to learn first hand the advantages and disadvantages of alternative transportation systems.

Living Arrangements

Before entering the Cooperative Living project, all of the residents were living in their parents' homes or in nursing homes or hospitals where they relied on family members or on a nursing staff to meet their needs for physical assistance. Thirty-four residents lived originally in the state of Texas, five came to the project from other states (Louisiana, Oklahoma, Kansas, and New Mexico), and one was from the Virgin Islands.

Chart 5:11 shows the living arrangements of residents before they entered the project. Eighteen persons were living with their parents in large urban areas (primarily in Houston or Dallas) before entering the project. Many of these persons were attending college at the time they moved in. Thirteen persons were living with their parents in small towns or rural areas, and usually in these situations opportunities were very limited for attending school, getting vocational training, or working. Nine persons entered the project from nursing homes (eight persons) or hospitals (one person).

Chart 5:11
Residence Before Moving to Cooperative Living



After living in the Cooperative Living project an average of 15.1 months, over four-fifths of the residents (82.5%) moved on to more independent living arrangements. Their places of residence after leaving the project are shown in Chart 5:12. Twenty-six persons moved into one of four apartment clusters in Houston that offer shared attendant and transportation services based on the Cooperative Living model. (The development of these clusters is discussed in Chapter 7.) Seven persons developed their own individual support arrangements where their needs for physical assistance were met by a private attendant or by a girlfriend or spouse. Five persons returned to their parents' homes, often because of medical instability. In such cases, the individuals could have remained in the project and recuperated from their medical problems (usually decubitus ulcers) except that their source of financial sponsorship in the project (TRC) was cut off if they were not able to maintain continuous involvement in school or vocational training. Two persons left the project to go to nursing homes or to a hospital because of medical instability.

Chart 5:12
Residence After Leaving Cooperative Living

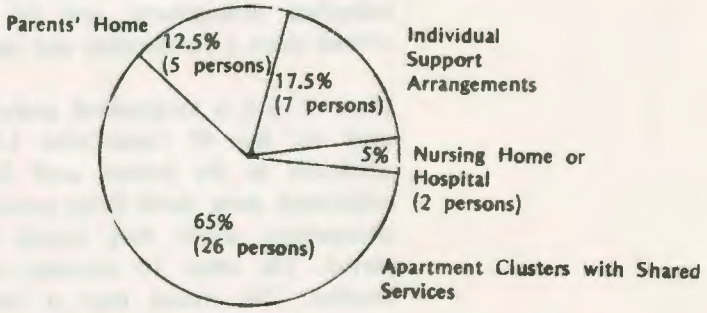
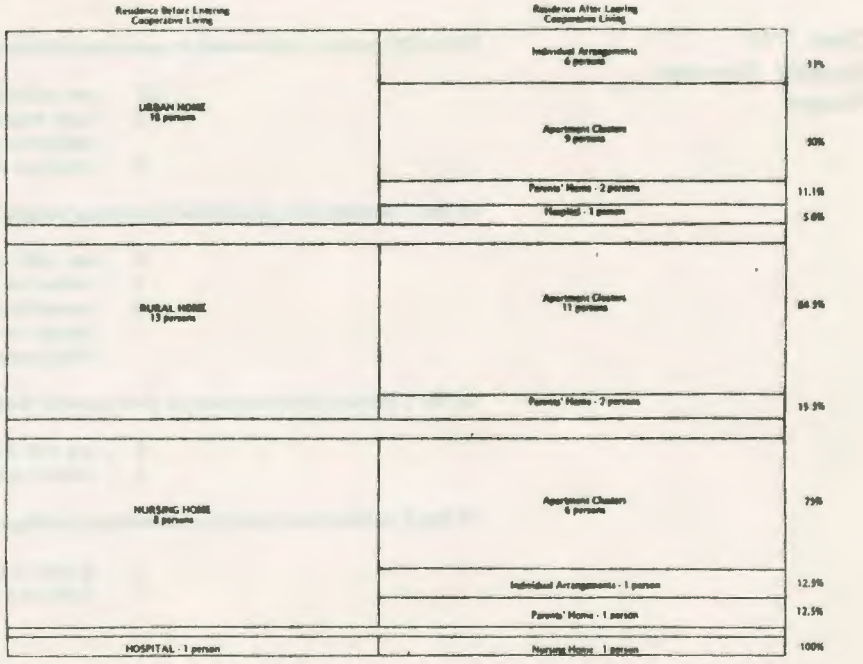


Chart 5:13 compares outplacement patterns for persons who came originally from urban homes, rural homes, nursing homes, or hospitals. Several comparisons are noteworthy.

Chart 5:13
Outplacement Patterns



The group of residents who came originally from urban homes had an unusually high proportion of persons who left the project to initiate their own individual support arrangements (33.3% as compared to 0% of persons from rural homes, 12.5% from nursing homes, and 0% from hospitals). This is a reflection of the fact that many of these persons had been attending college prior to entering the project and had gained valuable social experience, self-confidence, and an economic base which were important assets in becoming more independent and in managing the numerous responsibilities of an individual arrangement. The majority of persons who came from rural homes moved on to apartment clusters (84.5% as compared with only 50% of the persons from urban homes). This is generally consistent with the proportion of persons from nursing homes who left the project to enter apartment clusters (75%). Persons coming from these two settings (rural homes and nursing homes) had generally been more isolated socially and had not had an opportunity to begin involvement in college or vocational training. They consequently were less well equipped than the person from urban homes to handle the responsibilities of an individual arrangement, and the apartment cluster with shared services offered them a comfortable and structured setting.

Chart 5:14 is a longitudinal analysis of the sequence of living arrangements used by the 40 Cooperative Living residents from the time of their admission to the project until December, 1975. Thirty of the residents established quite stable living patterns, going from Cooperative Living to one arrangement where they stayed throughout the remainder of the study period. The other 10 residents continued to move from one setting to another. This means that at the end of the four-year study period (December, 1975), 28 persons were living in clusters, six were living in individual support arrangements, five had returned to their parents' homes, and one was living in an institution.

Chart 5:14
Resident Movement Patterns

Of the 26 persons who moved to apartment clusters after leaving Cooperative Living:

22	are still there
2	have moved on to establish individual support arrangements
2	returned to their parents' homes

Of the 7 persons who established individual support arrangements:

4	are still there
1	moved to an apartment cluster
2	moved back to their parents' homes for a few months and then moved into clusters

Of the 5 persons who returned to their parents' homes:

3	are still there
2	moved into apartment clusters

Of the 2 persons who went to institutional settings:

1	is still in a nursing home
1	went to an apartment cluster

These data indicate that for the majority of the project residents, the time they spent at Cooperative Living served as a transitional experience which they used as a preparation for moving into more independent living arrangements. A few residents preferred to return to a safe home or institutional environment, and some lacked the medical stability or problem-solving capability to become more independent in their place of residence.

Attitudes

Positive changes in self-concept and in attitudes were expected to be major benefits of the Cooperative Living project as it was being planned. Most residents have in fact reported significant changes in these areas.

Many of these changes cited by residents related to the opportunity to assume an adult role in society, which was not possible in their previous residential setting. When living at home with parents or in a nursing home, a disabled young person frequently finds it very difficult to get outside the role of child or of patient. Becoming an adult involves making decisions, managing time and activities, managing financial affairs, and anticipating problems and taking the initiative to solve them when they occur. Most of the residents assumed these new responsibilities for the first time in the Cooperative Living project. Some persons approached these responsibilities with great eagerness and some with hesitation and reluctance, but almost all residents took pride in assuming some increased degree of control over their lives. These feelings are expressed in statements by residents found in Appendix E.

Residents who previously lived with their parents usually expressed satisfaction about no longer being a burden on their families. This was usually tied to increased confidence that there were positive contributions they could make to other persons and that physical dependence on others did not mean one must always be in the role of recipient. This confidence in their ability to contribute as adults often had an important effect on self-esteem. For example, one quadriplegic who had just begun driving his own car to school reported immense satisfaction at giving an able-bodied student a ride. He reported this as "the first time in the nine years since I've been hurt that I ever helped somebody else with a physical task."

The recognition by residents that they had something to contribute to other individuals and to society was often manifested in efforts to secure part-time or full-time work. Their first paycheck was reported as an important experience by a number of individuals. Most individuals who began to work continued to take pride in their usefulness and in the financial independence it permitted. A few persons began to feel disillusioned by the work experience itself or by related problems such as the difficulty of living on a meager budget or the problems of losing important benefits such as coverage for medical care.

In the project, a number of individuals began for the first time to initiate close personal relationships. Many, in fact, had deliberately severed all such relationships at the time of their injury, and it was often a difficult process

to again consider this a serious option. A number of persons made this change. Nine previous residents of Cooperative Living are now married and three are living with another person in relationships that are functionally like marriages. As a result of seeing peers develop such relationships, a number of residents began to consider seriously for the first time their own potential as disabled persons to become marriage partners.

Modeling was an important factor in influencing residents' attitudes about their own capabilities and limitations. They frequently saw fellow residents doing things they previously had assumed were lost to them because of their physical disability. In addition to prompting reconsideration of major attitudes, modeling also taught residents new skills in interacting with other persons or in managing various areas of their lives, such as self-care or financial affairs.

Some residents experienced negative changes in attitude. Individuals occasionally came to Cooperative Living with high expectations about the project itself, about opportunities in Houston, or about their own capabilities. For a few persons, disappointments in these areas led to greater pessimism about their future and to passive acceptance of circumstances with little attempt to influence what happened to them. Such attitudes were manifested in social withdrawal and decreased levels of activity.

During the project, attempts were made to investigate and document possible changes in self-esteem and attitudes with standardized psychological tests. The Rotter Locus-of-Control Test and Tennessee Self-Concept Scale were used in two research efforts. One was a study comparing 14 Cooperative Living residents with a sample of 14 similarly disabled nursing home residents. A second study used a longitudinal design and compared the test scores of the 14 Cooperative Living residents with scores the same individuals made a year later after a number of them had moved into apartment clusters in Houston. The differences measured in both of these studies were not substantial. A number of factors could account for this. It is possible that there were in fact no substantial differences in attitudes. However, the researchers felt that open-ended interviews frequently revealed significant differences in self-concept and in outlook which the standardized measures used in the research did not reflect. In interviews, most nursing home residents showed less confidence in their ability to contribute to others and a more fatalistic attitude about their ability to influence their future than did residents of Cooperative Living. In the longitudinal study, most Cooperative Living residents expressed increased belief in their own competence in the follow-up interview as compared with the initial interview conducted while they were in the project.

Residents frequently viewed their experience in the Cooperative Living project as an important "stepping stone." The majority chose to move on to more independent living settings with the feeling that they outgrew a dormitory setting. This decision to move on is itself perhaps the clearest expression of increased confidence in self.

Medical Status

As independent living programs are developed, there are always legitimate concerns expressed by medical personnel who fear the frequency of medical problems that might be prompted by the care environment. This section is intended to shed some light on these concerns.

Chart 5:15 reflects medical problems that occurred while persons were living in the Cooperative Living project. The problems recorded represent the total of all problems experienced by all residents during their stay in the project. The problems are largely those that one would expect, such as urinary tract infections, skin breakdowns, and respiratory infections. One unexpected problem was the number of falls, burns, sprains and other minor injuries that occurred as a result of the residents' leading more active and mobile life-styles. A total of 53 medical complications were handled by the attendant staff with the guidance of the residents, who had been taught to assist in diagnosing and treating their medical complications. In 47 instances, the medical attention of a physician was required, and 21 hospitalizations resulted from complications experienced during residence. The major reasons for hospitalization consisted of such problems as severe cases of virus, urological complications, pneumonia, and routine reevaluation and follow-up hospitalizations. Concern over skin breakdowns is frequently mentioned as an area in which complications are expected to occur where medical surveillance is not available. Over the reporting period of the project, three hospitalizations were required for skin problems and each resulted in surgery. As the chart reflects, however, the majority of the skin problems were handled by attendant staff and by clinic and/or private physicians.

Chart 5:15
Medical Complications During Residence

Treated by	Urological	Skin	Respiratory	Falls	Others
Attendant Staff	1	23	23	0	7
Clinic and/ or Private Physician	15	20	4	7	6
Hospitalization	7	3	1	1	10

N = 40 persons

Chart 5:16 is a comparison of residents' frequency of medical complications prior to and after involvement in the Cooperative Living program. This chart reflects a sample of 18 residents, all of whom had a diagnosis of spinal cord injury at the C-5, or C-5,6 level, therefore offering a degree of commonality. Considering only hospitalizations for recurrent problems or follow-up and excluding the period of hospitalizations required for acute treatment, the residents had a mean of 1.15 hospitalizations per year prior to entering the Cooperative Living project. The mean number of admissions per year from admission to the end of the reporting date, 12/75, is .39.

These data indicate that residents experienced a lower frequency of medical problems requiring hospitalization while in the Cooperative Living project than they had experienced in their previous living environments.

Chart 5:16

Medical Complications

Comparison of Hospital Stays Per Year Prior to Admission to Cooperative Living vs. Number of Hospital Stays Per Year from Time of Admission to 12/75

RESIDENT	AGE AT ONSET OF DISABILITY	DISABILITY	TIME FROM ONSET OF DISABILITY TO ADM. TO C.L.*	TOTAL NO. OF HOSP. STAYS FROM ONSET TO ADM. TO C.L.	AVERAGE NO. OF HOSP. STAYS PER YEAR FROM ONSET TO ADM. TO C.L.	TOTAL TIME FROM ADM. TO C.L. TO 12/75*	TOTAL NO. OF HOSP. STAYS FROM ADMISSION TO C.L. TO 12/75*	AVERAGE NO. OF HOSP. STAYS PER YEAR FROM ADM. TO C.L. TO 12/75
1	14	C-5	9 years	5	0.56	4 years	1	.25
2	19	C-5	6 years	5	0.83	4 years	1	.25
3	17	C-6	6 years	6	1.00	4 years	1	.25
4	24	C-6	2 years	2	1.00	4 years	3	.75
6	16	C-5,6	6 years	2	0.33	4 years	0	.00
9	16	C-5,6	5 years	6	1.20	3 years	1	.33
10	18	C-5,6	5 years	4	0.80	3 years	0	.00
15	21	C-6	1 year	2	2.00	3 years	0	.00
16	19	C-5,6	2 years	9	4.50	4 years	0	.00
19	15	C-5,6	9 years	1	0.11	2 years	0	.00
20	17	C-5,6	2 years	5	2.50	2 years	2	1.00
21	18	C-5,6	3 years	3	1.00	2 years	0	.00
23	20	C-5,6	3 years	3	1.00	2 years	1	.50
30	18	C-5	8 years	5	0.63	1 year	2	2.00
31	15	C-5,6	4 years	3	0.75	3 years	2	.67
32	20	C-5,6	3 years	2	0.67	4 years	2	.50
33	16	C-5,6	11 years	15	1.36	4 years	0	.00
34	16	C-5,6	6 years	3	0.50	2 years	1	.50
					Mean = 1.15			Mean = .39

*Times were rounded to nearest year

The Cooperative Living project was designed to incorporate features of a good living environment for severely disabled young persons. A few models were available in this country such as Disabled Students Program at the University of Illinois at Champaign-Urbana and the Center for Independent Living at Berkeley. Some experience existed in other parts of the world such as the Het Dorp village in the Netherlands and the Fokus system of apartment clusters in Sweden. By and large, however, there was little experience to draw on, and the Cooperative Living program was viewed as an experiment to develop a model system with features the residents found desirable and supportive.

Initially, it was important to examine and evaluate the course the project was taking. One aspect of evaluation was an internal process of self-examination and improvement involving both the project staff and the residents. A second important element was a comparison of the Cooperative Living system with other alternative living arrangements for severely physically handicapped young adults. Comparison with other environments fostered a more analytic perspective and caused the staff to raise questions that otherwise might not have become apparent. It also enabled the staff to formulate judgments about different kinds of environments that seemed to be comfortable and supportive for different kinds of disabled persons.

From April through July, 1974, standardized interviews were conducted with disabled residents in the Cooperative Living project, the Moody Towers dormitory at the University of Houston, and six nursing homes. During the fall and winter of 1975, interviews were conducted with residents of four apartment clusters offering shared attendant and transportation services based on the Cooperative Living model. These interviews were based on the schedule in Appendix D. In many cases, respondents not only answered the specific questions posed to them, but also spent several hours talking about their own impressions of their particular environment. Interviews were also conducted with other members of the social system in various settings, such as personal attendants or floor counselors in the Moody Towers dormitory, and administrators or staff members of nursing homes.

The section that follows provides a brief overview of each setting, and then offers general conclusions about alternative living environments. The dimensions listed below serve as a framework for briefly describing each environment:

a. characteristics of the residence as a physical structure;

b. the location of the residence in relation to other elements of the surrounding community;

c. demographic characteristics of the resident population and types of disabilities represented;

d. the social system of the residence;

f. the supportive services provided;

g. the managerial structure and procedures; and,

h. the costs and methods of financing.

Descriptions are written in the present tense, though they refer to the time period of the study which is indicated for each setting. The Cooperative Living project is briefly summarized according to this comparative format. More detailed information on this environment can be found in Chapter 2.

The Cooperative Living Project
(fall, 1974, winter, 1975)

Physical Space

The physical space of the Cooperative Living project is a dormitory-style arrangement located in a new and attractive building owned by TIRR. Each of the 14 residents has a private room with a lavatory and commode. The project has a shared, roll-in shower room, an attendant room for staff members, and an office for the project managers. Dining and recreation rooms and a laundry room are shared with 14 Institute in-patients who live on a separate hallway in the same building. The spatial arrangement of the project fosters the kind of social interaction typical in dormitories, where individuals have some opportunity for privacy but where frequent group interaction occurs in the dining and recreation rooms, in the wide hallway, and in the rooms of certain residents. Residents feel that the architectural features of the building have made it possible for them to be more independent in physical functioning. The major change they would like to make in the design of the space is to avoid its more institutional features, including a single long hallway and tile floors. They also would welcome larger individual rooms, a covered parking area to load and unload wheelchairs, and a larger outdoor lawn or garden for socialization.

Location in the Community

The project building is located in a near-downtown neighborhood with a varied mixture of once-elegant old homes, rather dilapidated small businesses, and newly-constructed townhouses. The neighborhood is not homogeneous or socially cohesive, and the Annex building remains a largely separate social and physical entity. Project residents do visit a few business locations within easy rolling distance (two bars, a restaurant, and a convenience grocery store), and they know a few persons living in the area who frequently stop to talk with any residents who may be sitting outdoors in the evenings.

The Residents

Eight of the 14 residents of the Cooperative Living project are male, spinal cord injured quadriplegics. Two other male quads are disabled by polio residuals and by Chondro-osteodystrophy. The other male resident had become a hemiplegic from a head injury and later a paraplegic from a spinal cord injury. The three females in the group include one post-polio paraplegic, one post-polio quadriplegic, and one quadriplegic with myelodysplasia. Five members of the group thus grew up with their disabilities, and nine were spinal cord injured persons who became disabled in late adolescence. All of the group members, except one female paraplegic, require substantial physical assistance with their daily care needs. The residents range in age from 19 to 33 years. One male and one female resident are black and the others are Anglos. Ten of the residents are from Texas and four are from other states. Seven members of the group are students at the University of Houston, three are students at a junior college, and four are in vocational training programs at the Work Activities Program sponsored by TIRR.

The Social System

The residents generally form a cohesive group and interact frequently with each other. There are, however, two residents who choose to participate less actively in group socialization, and two other residents who are viewed rather negatively by the group and are ostracized to some extent for making unreasonable requests for physical assistance from attendants and for not adhering to the value strongly supported by most residents of maximizing their personal initiative. Most residents welcome interaction with the group and view this socialization as supportive and enjoyable. The rooms of certain residents, the hallway, and in pleasant weather, the wide sidewalk outside the project, are frequent focal points of interaction which occurs primarily in the evenings and to some extent on the weekends. A staff of 10 attendants is also a part of the project social system. In general, the attendants interact with the residents on the basis of friendship, though in a few cases the relationships are business-like.

Outside Activities

All of the residents are regularly involved in daily activities outside the project. Seven are students at the University of Houston, three are junior college students, and four are in vocational training programs. The project van makes trips daily to each of these locations, which are all within 15 minutes of the Annex building. Occasionally, some members of the group will make arrangements to use the project van to attend other activities such as football games, a rock concert, or a trip to the beach. Most of the residents have some friends outside the project, mainly through contacts at school or vocational training, but most residents do not frequently invite friends to visit them at the project. Leisure activities and social contacts are largely conducted with other members of the Cooperative Living group. None of the residents are dating on a regular basis.

Supportive Services

Supportive services in the project, including meals, transportation, and non-professional attendant assistance, are organized on a shared basis. Meals can be ordered from the Institute food service, though many residents choose to order some meals from outside the project. A microwave oven and refrigerator are located in the attendant room, though this room is not really equipped for preparing more than snacks or reheating meals cooked elsewhere. Several persons have their own small refrigerators.

Transportation is provided in a GMC step van which can carry seven persons at one time. Trips are scheduled with a sign-up sheet.

Attendant assistance is shared by the group, and staffing patterns are arranged to correspond to the daily activity schedules of the residents. In the mornings and evenings, two, or sometimes three, persons are on duty to get people up and help them with showers and bowel programs. During the middle of the day and after midnight, one attendant is available. Scheduling of requests is by sign-up. This shared system has important cost advantages and teaches residents to budget their use of attendant help. Its major disadvantage as viewed by the residents is that individuals cannot readily leave the project with an attendant to accompany them since the attendant

staff is responsible to the group rather than to single individuals.

Needs for medical care are met using community resources. Emergencies are handled by general hospital emergency rooms with transportation by regular ambulance. Routine problems are usually handled through visits to an outpatient clinic at the main Institute building.

Management

The Cooperative Living project is managed by a four-member Resident Management Council whose members are elected every six months. The Council has devised a division of labor in which one member keeps accounting records, one recruits and hires attendant staff, one is responsible for the supervision of the building and the van, and one handles coordination with supportive systems at the main building such as the housekeeping or maintenance departments. Each council member is responsible for scheduling and supervising the attendant staff for a week at a time on a rotating basis. This has some disadvantages in establishing clear authority with attendants, but offers the advantage of sharing the 24-hour-a-day responsibility for monitoring the operation of the attendant system. A number of standardized procedures have been developed for scheduling staff working hours, scheduling requests for physical assistance, keeping payroll records, and other tasks.

Costs

Costs for room, meals, and services provided by the project are summarized in Chart 6:1.

Chart 6:1
Monthly Living Costs in the Cooperative Living Project

SERVICES	CATEGORY 1	CATEGORY 2	CATEGORY 3
Room Rent	$110	$110	$110
Meals*	75	75	75
Attendant Assistance**	120	160	200
Transportation	55	55	55
Personal Expenses	130	130	130
TOTAL MONTHLY COST	$490	$530	$570

*Records are maintained of all residents' meals and they are billed for food actually ordered. The figure cited is an average amount.

**There are three categories of attendant assistance. Criteria defining these categories can be found in Appendix C.

Almost all residents are clients of the Texas Rehabilitation Commission (TRC) and receive assistance with their living expenses from this agency. The average monthly subsidy from TRC is $279.00. They also receive rent subsidies from the Houston Housing Authority with the average monthly amount being $79.00. Most residents receive SSI checks, and a few are eligible for SSDI payments. The welfare department provides no assistance

to Cooperative Living residents because they are living in a group setting which is technically licensed as a hospital.

Summary

In general, the Cooperative Living project provides a comfortable and supportive living environment for individuals who want to establish their independence for the first time from a family or institutional setting. Such persons frequently welcome the social closeness of peer group interaction, the closeness of attendant help, and the existence of an ongoing management system as they leave former sources of security. The project provides an environment where individuals can test their ability to get along with attendants, their ability to manage their own time and money, and their capabilities in academic or vocational training programs. In this setting the risks of failure are less formidable than they might be in a single apartment where each individual would have less social closeness and more managerial responsibilities to handle alone. In time, however, many residents outgrow the close-knit dormitory-style system and prefer to move to an apartment setting that offers greater privacy and the opportunity to develop close personal relationships.

The Moody Towers Dormitory, University of Houston Campus
(spring and summer, 1974)

Physical Space

Moody Towers is a two-year-old dormitory with twin 18-story towers, one for male and one for female residents. Located between the towers are a large lounge, a cafeteria, various offices and meeting rooms, smaller lounges, a snack bar, post office, and recreation areas. Disabled students live on the first and the sixteenth floors of each tower where bathroom facilities have been modified for wheelchair accessibility. The first floor of each tower has double rooms and the sixteenth floor has singles. In general, the disabled students feel that the dormitory meets their needs architecturally, though there are some problem areas. Features they cited as problems included laundry facilities which are located on the roof and can be reached only by stairs. Funds are not sufficient to make bathroom facilities on each floor accessible which means that students in wheelchairs must live on certain floors, a factor that hinders their full integration into the dormitory social system. Several students feel the rooms are too small for storing extra wheelchairs and equipment. A number of them also expressed concern about the safety of persons in wheelchairs living on the sixteenth floor in the event of fire or other emergency situation in which elevators could not be used. (The two elevators in each tower are located in a single elevator shaft.)

Location in the Community

Substantial efforts have been made to make the University of Houston campus wheelchair accessible. Disabled students living in Moody Towers thus have access to all of the facilities typical of a university campus. Almost all of these can be reached by electric wheelchair, but the distances involved require a sizeable effort for a person in a manual chair. Heavy rain during

some seasons also hampers travel around campus. Few facilities or businesses immediately surround the campus; consequently, involvement in activities outside the campus perimeter almost always requires long distance travel, and few disabled students have transportation available. Three persons do own cars or vans, though in one case the vehicle must be driven by able-bodied friends. For the most part, the disabled students feel that "the community" for them means the campus. Many do not leave its boundaries during the course of a semester except on school vacations. Some disabled students regret this degree of separation from the mainstream of society, and others find it enjoyable.

The Residents

The group of students in wheelchairs who live in Moody Towers is made up of six females and seven males ranging in age from 18 to 28 years. Of the females, two are paraplegics and four are quadriplegics. Among the males, three are paraplegics and four are quadriplegics. Three of the six females and four of the seven males need daily attendant assistance. Of the 13 persons, 10 grew up with their disabilities and three became disabled in adolescence by spinal cord injuries. This proportion differs markedly from the residents of the Cooperative Living project, where nine of the 14 persons became disabled in adolescence. All of the students are Anglos. Nine are from Texas and four are from other states (Connecticut, North Carolina, and Kansas). Nine are undergraduates, and four are graduate students in English, social work, and law (two persons).

The Social System

In the dormitory generally, residence on a given floor is reportedly an important factor affecting social interaction, particularly for female students. Most students are at least acquainted with everyone on their floor, and any individual's closest friends tend to be persons living on the same floor. Other social groupings based on shared personal characteristics cross-cut this geographically-based pattern; however, these groupings can often be identified in the cafeteria during meal time when certain types of persons repeatedly sit together in the same location. The group of disabled students with their set of able-bodied friends constitutes one such group that routinely eats together. Each disabled student's social network is shaped to some extent by these two general patterns, one based on residential proximity and one on the shared trait of being disabled.

Three of the four disabled female students on the first floor of the women's tower have able-bodied roommates who serve as their personal attendants. These seven persons and several other able-bodied women on the floor form a cohesive group who interact together. Disabled members of this group like the cohesion it provides and view the group as an important source of role models and of support. One of the male disabled students interacts frequently with the females in this group, usually joining them for meals in the cafeteria.

The other two disabled female students live in single rooms on the sixteenth floor and need no attendant assistance. They dislike being viewed

as part of a group of disabled students. Their decisions to remain apart from the group of disabled students is accepted readily by the other female students.

Four of the disabled male students live on the first floor of the men's tower. Three have able-bodied roommates who serve as their personal attendants. These four students and their roommates interact occasionally with each other, but all four of them have their own primary social contacts outside the dormitory social system. One of these males frequently serves as a contact broker (Wolf, 1956) for the cohesive group of female disabled students, introducing them to his large social network of fellow students and other contacts.

The other three disabled male students live in single rooms on the sixteenth floor. Two of them are actively involved in wheelchair sports and other social activities outside the dormitory. They heartily reject association with other disabled students and regret the formation of a cohesive group of female students, which they feel fosters stereotyping by able-bodied persons. The third disabled male student on this floor has an able-bodied attendant who lives in another room on the floor. He has few social contacts.

For the most part, the male disabled students are much less cohesive as a group than the females, though one frequently joins the female group. Some keep largely to themselves, and the others cultivate social contacts through activities outside the dormitory. Three of the males are resented to some extent by all of the other disabled students because of their outspoken refusal to interact regularly with the others.

In general, the Moody Towers students echo a socialization pattern followed by many residents of the Cooperative Living project. Among these students, social cohesion and frequent interaction with a group of peers is welcomed early in the process of becoming independent from their families. Later, as they develop other social contacts through involvement in activities outside the group, many persons outgrow the desire for peer solidarity and come to prefer greater privacy.

Outside Activities

Each person spends some part of his or her day attending classes and doing academic work around the campus. One resident has a part-time job on campus as well. Three of the students spend a substantial amount of time attending activities of organizations apart from the University. The organizations are a wheelchair basketball team in two cases and a church group in the third. One student is actively involved in the University debate team. Three students occasionally attend informal social activities organized by fellow graduate students in their departments. Two students are dating on a regular basis. The majority of disabled students in Moody Towers are thus actively involved in activities outside their residential system, though five of the 13 students have virtually no involvement of this sort. They reflect a higher rate of involvement in activities outside the residential system than is true for the group of Cooperative Living residents. This is

probably due in part to the ready availability of organizations and informal social groupings on campus. It also reflects the fact that Moody Towers residents are generally older, farther along in school, and for these reasons, probably generally more mature and experienced than the Cooperative Living residents.

Supportive Services

Meals are provided in the dormitory cafeteria. Many of the disabled students regularly eat together as a group which also includes a set of able-bodied friends. A few disabled students reject this grouping and make a point of sitting apart in the cafeteria.

The University has an Office of Handicapped Student Affairs which organizes readers for blind students, assistance with registration and orientation to the campus, library assistance, volunteer pushers, and counseling. This office does not play a role in coordinating attendant service or transportation. Each individual must therefore find and hire his or her personal attendant and provide for needed transportation.

Seven of the 13 residents have personal attendants who are their roommates and one person has an attendant who lives in a nearby room. Attendants are usually found through personal contacts or through ads in the school newspaper or placement office. In a few cases, disabled students have hired close personal friends as attendants, but most persons feel this is unwise because it reportedly destroys the friendship. The interaction between disabled students and attendants is usually very intensive in terms of the amount of time spent together, and such relationships rarely last more than one semester. Difficulty in finding a compatible attendant and the intensity of the relationships are viewed as major problems by all but one of the disabled students, yet none of them have initiated arrangements that might modify this situation, such as having two different persons assist with morning and evening routines. Disabled students feel that the great advantage of having a private attendant is the freedom it offers to go out with the attendant without any obligation to coordinate schedules with other persons.

Several Moody Towers residents have virtually no transportation except for their wheelchairs. Two own cars they drive themselves. One owns a car he can drive, but he requires assistance in transferring and loading his wheelchair. One student has a van which his able-bodied attendant drives. The other students must rely on able-bodied friends who are willing to provide transportation to any activities off campus. Most disabled students make an effort to find friends who are willing to provide this assistance.

Management

The services organized by the Office of Handicapped Student Affairs are supervised by an Associate Dean of Students who has two graduate student assistants from the University's School of Social Work. Most students feel it would be helpful if the Office of Handicapped Student Affairs could serve as an employment service for attendants, but resources are not available to provide this service.

Costs

Students in Moody Towers pay a standard room and board cost of $170 per month. The usual payment for attendant help is also room and board, which makes a total monthly cost of $340 for students who need physical assistance. In three cases, attendants are paid an additional monthly fee of about $50 beyond room and board by individuals who are very severely disabled and who thus need a great deal of time from an attendant. This compares with a usual monthly cost in the Cooperative Living project of $570, which also includes a fee for transportation. (A personal expense estimate of $130 is also included in the Cooperative Living estimate.) The living expenses of some Moody Towers residents are subsidized in part by the Texas Rehabilitation Commission, though in four cases these expenses are borne by the students' families. Four of the students receive SSI or SSDI checks which they use to cover a portion of their expenses.

Summary

The Moody Towers Dormitory provides a comfortable living environment for a number of students who see its greatest advantage as the convenience of being located on campus and not needing to rely on transportation arrangements to participate in a wide range of activities. Several students also mentioned the advantage of close association with other disabled students who are important as role models and as sources of emotional support. Residents view the major disadvantages of their living environment as lack of privacy and a quiet atmosphere, separation from the mainstream of society, and the continual problem of finding and keeping a reliable attendant. A few students report that they dislike being associated so closely with a number of other disabled students because it leads to stereotyping.

Nursing Home Environments
(spring and summer, 1974)

Six nursing homes are included in the study of living environments which have 1, 2, 2, 3, 6, and 9 young disabled residents respectively. They are discussed jointly since the living environments are similar in most respects. Exceptions to the general pattern and possible reasons for these are noted.

Physical Space

The six nursing homes studied are generally similar in physical design, though some are newer, are decorated more expensively, and are in better repair than others. All have long hallways with double rooms on both sides and nursing stations located at intervals. There are shared dining rooms, lobbies, and recreation areas in each home, along with meeting rooms and administrative offices. In general, the facilities are well-designed for wheelchair accessibility, though in some homes the bathroom or dining room spaces may be crowded. Young disabled residents usually feel that the physical structures have a very institutional flavor, primarily because of the long hallways, standardized double rooms, and the presence of nursing stations. In addition to changing these institutional features, most young persons would like to have more outdoor areas that are wheelchair

accessible and designed for socialization, and more private space that is not shared with a roommate.

Location in the Community

All of the homes are located in suburban areas which in some cases are a sizeable distance from the city. Two of the homes are located within rolling distance of small shopping centers where young disabled residents visit stores, convenience food places, and bars. Such trips are usually discouraged by the home administrators, however, because they involve travel by wheelchair along fairly busy streets.

Contact with the community beyond the home thus usually requires transportation arrangements. One resident has his own car and can visit locations where someone will meet him to help with transferring and loading his wheelchair. In one of the homes, a special transportation service has been arranged by an outside non-profit volunteer organization. This organization owns a van and takes the nine residents to doctors' appointments, to church, and on occasional leisure and shopping trips. In most cases, however, young disabled persons must depend on family members or friends to transport them to any activities outside the residential system in the larger community. For many, the residence thus becomes a closed system.

The Residents

The young disabled nursing home residents are a more diverse group than is found in either the Cooperative Living or Moody Towers environments. They range in age from 18 to 54 years old. Thirteen of the 23 individuals were disabled in adolescence or early adulthood and the remaining 10 persons have had their disabilities since childhood. Unlike the Cooperative Living or Moody Towers residents who are usually leaving home for the first time, a number of the nursing home residents have had a variety of life experiences before becoming disabled which include ranching, working as a petroleum engineer, and working as a clerk in New York City. There are 17 males and six females. All are Anglos. A few members of the group are involved in activities such as social occasions sponsored by the Muscular Dystrophy Association or personal activities such as pen and ink drawing. In contrast to the residents of other environments studied, the nursing home residents do not identify themselves through outside affiliations as students, vocational trainees, or persons with occupations.

The Social System

In each nursing home the major components of the social system are elderly patients and staff members. In all but a few cases, the young disabled residents report that they do not really belong in this social system, which they feel is designed for persons with different needs. In most instances, the young residents do interact amiably with the staff and with elderly patients, though there are few warm and close friendships. Occasionally, close relationships do develop with nurses aides, and for a number of young residents such staff members are virtually their only friends. In some cases, young residents largely withdraw from social contact

within the home. In others, direct hostility develops with the staff over issues such as use of alcohol or drugs, restrictions on visitors, or sexual relationships with staff members, fellow residents, or friends from outside. Of the 23 young persons interviewed in nursing homes, only one had developed a wide network of close friends among elderly patients and staff.

In the two homes that had six and nine young disabled residents, group social cohesion developed among these sets of young residents. (Two-person dyadic relationships were also formed by some members of the groups.) At one home, this interaction also included friends who visited from outside the home. By contrast, such cohesion has not developed in the three homes with groups of two or three young residents. This difference might be attributed primarily to the numbers of young persons in the system. With six or nine members of the group, each individual has some choice of close friends, and relationships in the group as a whole can be less intensive than in a small group of two or three persons. There may also have been other factors operating in the two homes with six and nine young persons that fostered group solidarity among the young residents. In one case, the home administrator was himself a young paraplegic who purposely fostered cohesion among the six young residents. In the other home, there formerly had been as many as 25 young persons who as a group had been involved in direct confrontations with the administration. This group of persons was thus united by their opposition to a common adversary. Most members of the larger group of 25 young persons had left the home by the time of the study, but some cohesion may have remained from this earlier period among the nine residents still living at the home.

Outside Activities

Very few of the nursing home residents have ongoing involvements beyond the boundaries of the residential system. Among the group of 25 young persons that had formerly lived in one of the homes, there had been six individuals who were attending the University of Houston. They relied on the transportation service provided by an outside non-profit organization. Reportedly, it was very difficult to attend school while living in a nursing home. Major problems cited included the distance of the home from school and the difficulty of getting transportation, problems in getting up to meet a regular schedule, and difficulty in finding a quiet and private place to study.

Among the current residents of the six homes, one leaves the home frequently in his own car to visit friends, one is picked up occasionally to attend activities of a local muscular dystrophy chapter, and one is beginning involvement in a vocational evaluation program. But for most persons, trips outside the home are sporadic and must be initiated by outside friends or family members or by the non-profit organization that provides transportation to residents of one of the homes. None of the nursing home residents are involved in a regular programmed activity outside the system such as school, work, or vocational training.

Supportive Services

Meals and nursing service are not separable services in the nursing home. They are purchased along with room rental as part of a care package, which by law includes certain other services such as recreation. Almost all of the residents studied are certified for level IV or skilled nursing care, which is governed by licensing regulations that specify professional qualifications of various level staff members. In this system there is little flexibility to allow residents to direct their own care or manage their medications. The nursing home is designed to function as a self-contained system, so there is no provision for transportation service to foster or support outside involvements of residents. The one exception to this generalization has been mentioned above. At one home, which had as many as 25 young persons at one point in time, a non-profit corporation was formed by friends of the residents and by one staff member to purchase a van and provide transportation. Sometimes the group could afford to pay a driver, and at other times this was done by volunteers. The provision of transportation made it possible for the residents of this home to be much more active than is typical of the other young nursing home residents.

Management

The nursing homes are managed by an administrator and supporting staff in a hierarchical system. Qualifications of management personnel at various levels (such as the administrator, director of nurses, and shift supervisors) and the lines of authority are determined by licensing regulations. Five of the homes studied are owned by one large national chain and one is owned by another such chain. Each home is thus part of a larger management system.

By law and nursing home policy, a number of rules are imposed on residents of nursing homes which have significant impact on the life-styles of young residents. These include curfews, visiting hours, prohibitions on the use of alcohol and nonprescription drugs, and a 72-hour limitation on the amount of time an individual can be away from the home, which restricts opportunities for visiting family or friends. In one home, the young residents sought to establish a council to represent them as a group in discussing grievances with the management structure, but this proposal was rejected.

In contrast with the Cooperative Living or Moody Towers residential environments, nursing homes are highly standardized and regulated institutions operated by a professional managerial structure. In this system, the residents have a defined role as patients which does not allow them much voice in managing either their own lives or the system as a whole.

Costs

Costs paid by Medicaid for skilled nursing care are $513.00 per month in Texas. This amount includes room, board, laundry, nursing care, and activities organized by a recreation director, which young residents take part in only rarely. It does not include transportation. All of the young disabled persons studied are supported in the home by vendor payments made on their behalf by the Department of Public Welfare, which pays the total cost of their care. Residents also receive $25.00 per month for personal use.

Summary

The nursing home setting provides a comfortable environment for young disabled persons who do not have the capability or the desire to assume the responsibility of managing their own affairs. A few disabled young persons were interviewed who welcome the security this setting provides and would not want the obligations one must assume to live in the Cooperative Living or Moody Towers settings. These responsibilities include managing finances, directing attendant help, and meeting commitments to outside organizations such as college or vocational training programs. One individual who likes living in a nursing home has developed an active lifestyle in this setting which includes pen and ink drawing, a great deal of social interaction with elderly patients and staff within the environment, and several trips a week to visit friends or just drive around in his own car. Three others who like this setting are much less active. They would prefer to live in an institutional setting occupied only by young persons. Though these persons find a few of the nursing home policies restrictive, they have no desire to move into a setting that would permit and require greater personal independence.

All of the other young nursing home residents have largely negative feelings about their living environments. A major cause of complaint is the closed and self-contained setting where residents spend virtually all of their time and have few opportunities for outside involvement. Nursing homes correspond to a great extent to Goffman's definition of a total institution (1961), and many young persons feel they are "warehoused" in this environment, which was also reported in Miller and Gwynne's study of such settings in England (1972). Young persons generally find that rules of the home eliminate many everyday pastimes they would like to pursue (such as drinking) and thus dictate a life-style unlike the one they would choose. A third major reason for disliking nursing homes is the elderly population. Most young residents get along well with a few elderly individuals, but they dislike the general atmosphere in which persons are losing their physical and mental competencies and in which there is little involvement outside the boundaries of an ingrown system.

The Four Apartment Clusters (fall, 1975, and winter, 1976)

From the spring of 1974 through the fall of 1975, four apartment clusters were developed in Houston that offered shared services based on the Cooperative Living model. Three of these were initiated by former residents of Cooperative Living, and one was developed by a group of young disabled residents of a nursing home. Three of the apartment complexes are owned by private developers. One is owned by Goodwill Industries. In all four cases, autonomous non-profit corporations have been formed by the residents to provide shared transportation and attendant service. The evolution of the clusters is discussed at length in Chapter 6. The apartment complexes and related service corporations are listed in Chart 6:2.

Chart 6:2
Houston Apartment Clusters

APARTMENT COMPLEX	NON-PROFIT CORPORATION PROVIDING SUPPORTIVE SERVICES
Westbury Country Village	Independent Life Styles, Inc.
Independence Hall Apartments	Free Lives, Inc.
Spring Tree Apartments	Creative Handicaps, Inc.
French Village Apartments	Quality Living, Inc.

Physical Space

The four clusters are located in different types of apartment settings. Westbury Country Village is a new project with 140 units owned by a development company. The group of young disabled persons who formed the Independent Life Styles Corporation were able to talk with the developers before construction was completed, so several modifications could be made in 14 two-bedroom apartment units. The most important of these modifications include lowered light switches, ramps and curb cuts, roll-in showers, hardware that can be managed by quadriplegics, and low pile indoor-outdoor carpeting. A concrete ramp was also installed in one of the swimming pools. The grounds of the project and the pool are attractive, and residents enjoy socializing outdoors. The 20 residents report that these apartments generally meet their needs in terms of accessibility, although the kitchens are not modified and are difficult for some persons to use. All of the modified units have two bedrooms, which means that many persons can afford them only by having a roommate. While this is considered desirable by many persons, there are individuals who would prefer an apartment alone but cannot afford a unit of this size by themselves.

The second cluster is located at Independence Hall, a 281-unit project for elderly and handicapped persons built with HUD support by Goodwill Industries. One wing of this large complex is set aside for use by persons who share attendant service and transportation provided by the Free Lives Corporation. These apartments were designed from the outset for wheelchair accessibility. They have roll-in showers, accessible kitchens, low pile carpeting, and appropriate hardware and electrical outlets. There are efficiencies and one-bedroom units in this cluster. Residents feel they are well-designed for wheelchair accessibility. The only architectural features they reportedly dislike are a long, bare exterior hallway that links the apartments and rather spartan grounds that have few trees and shrubs and do not encourage socialization outdoors.

The third cluster is located in the 132-unit Spring Tree Apartments which are about 20 years old and were being renovated at the time a group of nursing home residents were seeking to start a housing cluster. Because of these renovations, a block of apartments were vacated and made available simultaneously, and minor modifications could be made. Modifications

include widened doorways and ramped entrances and curbs. The cluster has both one and two-bedroom units which house 18 disabled residents and several live-in attendants. The major architectural problem reported by residents is the lack of roll-in shower facilities. Most persons must therefore take bed baths or transfer into a chair in the bathtub. As in most older apartments, there are more needs for maintenance than would be true of new units. The kitchens are not readily accessible, but most residents report that they could not cook by themselves anyway. The apartments are located around attractively landscaped courtyards which the residents enjoy.

The fourth cluster is located in the 444-unit French Village complex. Like Spring Tree, these older apartments were being renovated at the time a group of Cooperative Living residents were planning to leave the TIRR Annex building. Six two-bedroom units were available for the group of 10 persons, and minor modifications were made to widen doorways and ramp entrances. One resident reached an agreement with the apartment managers that permitted his father to remove the bathtub and install a roll-in shower. As in Spring Tree, major architectural problems at French Village are the lack of roll-in showers, kitchens that are not ideal for use from a wheelchair, and the need for ongoing maintenance in an older structure. These two projects illustrate the important point, however, that it is not necessary to construct a new and ideally accessible physical structure in order to develop community living alternatives for persons with physical disabilities.

Location in the Community

The clusters are all located in suburban residential areas of the city. In three cases, the apartments occupied by disabled persons are located in close proximity to each other within large complexes occupied by the general populace. In the Independence Hall project, owned by Goodwill Industries, the entire population is elderly or handicapped. One of the clusters is within easy rolling distance of a shopping center. The others are located approximately five minutes by van or car from shopping facilities. Each of the clusters is five to 10 minutes from the freeway that circles the city, so they are roughly equidistant from downtown. This usually means a drive of approximately 30 minutes to the University of Houston where a number of residents are students. On the whole, residents of the clusters report that they feel more a part of the mainstream of life in the community than is true of the other settings studied. Many have formed friendships and interact frequently with able-bodied persons who live in the same apartment complex.

The Residents

Each of the clusters is stereotyped among the disabled population of Houston as having a certain type of resident. To a large extent these stereotypes do reflect general differences between the projects.

The residents of Westbury are viewed as being the most mature and financially independent of the clusters. They range in age from 19 to 35. A number of these persons have finished college and are working. Several are

in graduate school at the University of Houston, and others are in their junior or senior years of school there. Several residents are also on full disability pensions from the Veterans Administration which provide them a comfortable income. Five of the 20 residents are married or plan to marry soon.

Most members of the group of 11 residents at Independence Hall are attending school at the University of Houston or a junior college. A few are in vocational training programs. They are generally viewed as an active group with ongoing involvement in activities outside the residential system. None of the residents are married, though several are dating. They range in age from 19 to 26 years old.

The Spring Tree cluster is usually identified by the general disabled population of Houston as being made up of persons from one nursing home. This is not true in all cases, but the great majority of residents do share this common background. The cluster is also managed by a former employee of the nursing home. Most residents of this project are not actively involved in ongoing activities such as school or work. They spend most of their time socializing at the project. A few persons are students at the University of Houston and a few are in vocational training programs. None of these residents are currently married. They have a wider age range than in the other clusters, with some persons under 20 and several in the 40's and 50's.

Six of the residents of French Village are involved in vocational training programs and four are attending the University of Houston or a junior college. They are all thus involved in outside activities, though all are at early stages of involvement and will require some time before they are ready to seek employment. As a group they are generally less mature and further from financial independence than is true of the residents of Westbury Country Village or Independence Hall. None are married, one is dating. They range in age from 20 to 35 years.

The Social System

For the most part, disabled young persons living in the apartment clusters are more fully integrated into the general population than in any of the other environments studied. This is most true of the Westbury cluster where the 20 disabled members of the Independent Life Styles corporation are dispersed around the complex. They have formed many friendships with persons living around or above them in second story apartments, and many also have numerous friends from outside the complex entirely. Some of the disabled residents interact with other members of their group frequently, but there are many who have minimal involvement with other members of the group. This is particularly true for persons who are married or dating frequently, for persons who have their own cars and do not use the shared transportation service, and for persons who have developed an outside network of friends through their work settings or through graduate school.

The eleven members of the Free Lives Corporation living at the

Independence Hall apartment complex maintain some degree of cohesion as a group. However, within this group are several smaller groupings of two or three friends who interact more often, frequently eating together and sharing leisure time activities. Residents of this project also spend time with friends from outside the apartment complex, though this seems to be less prevalent than at Westbury. There appears to be less interaction between the Free Lives residents and other residents of the apartment complex as a whole than is true at any of the other clusters. This is probably due in part to the fact that this group of Free Lives apartments are located in a separate exterior hallway apart from the other units in the complex, whereas there is greater spatial dispersion in the other complexes. It also may reflect the fact that the complex as a whole is designed for the elderly and handicapped and thus is not considered by the Free Lives residents as an opportunity for mixing with the general population.

At the Spring Tree complex there initially was a great deal of social cohesion among the 18 members of the Creative Handicaps Corporation. This was probably based to an important extent on cohesion that developed among the same set of persons when they were living together in a nursing home. In this setting, they participated as a group in several confrontations with the administrators of the home. Consequently, their establishment of the apartment cluster was viewed as a group solution to a shared dilemma, and the group felt strongly about not "leaving behind" at the home any residents who wanted to join them. This strong attitude of loyalty persisted for a number of months. At the time of the study, however, several members of the group had become disillusioned with most of its members because they had not become involved in school or vocational training which was expected once everyone was out of a nursing home environment. The more active persons are planning to move next door to another apartment complex, Villa Madrid, where they can still share the day system of attendant service and transportation, but will not be identified with a group of persons who "sit around all day." In addition to this social split, there have also been new residents who joined the Creative Handicaps cluster who had never lived in the same nursing home, and they too have made group loyalty and cohesion less intensive than it was initially. Within the group of 18 residents, there are several smaller groupings of three or four close friends who spend time together. Most members of this group also interact frequently with able-bodied residents of the Spring Tree complex. In general, they have few social contacts beyond this sphere.

The 10 members of the Quality Living Corporation who live at the French Village complex form a relatively cohesive group. As in each cluster, there are a few individuals who are not fully incorporated into the group social system. Six of the 10 persons are involved in the same vocational training program, which may also foster their cohesion through shared experiences and concerns. These individuals have formed many friendships with able-bodied residents of French Village. As at Spring Tree, they generally have few social contacts beyond the apartment complex except for daytime interaction at the University of Houston or at the vocational training program.

Outside Activities

Almost all of the residents at Westbury are regularly involved in outside activities. Half are employed and half are attending school, either at a junior college or as undergraduate or graduate students at the University of Houston or Rice University. Many have their own cars or vans and are involved in outside social activities. These activities include involvement in organizations, such as the Paralyzed Veterans of America, in addition to personal social activities. The residents of this cluster are generally more financially independent or closer to this status (juniors or seniors in college) than is true at any of the other clusters.

The 11 residents of Independence Hall are all either in vocational training programs or are students at the University of Houston with the exception of one individual who is working and one who is establishing a wheelchair repair shop in his apartment. Some members of the group are dating or are otherwise active socially, whereas others have few involvements outside the residential system beyond their primary daytime involvement.

The majority of the 18 residents of the Spring Tree cluster are not involved in regular activities such as school or work, though a few are students at the University of Houston or are in vocational training programs. Two are actively pursuing an educational program called the University Without Walls which does not involve regular classroom instruction. Several other residents also sit in on University Without Walls discussions that are conducted at the project, although they are not themselves enrolled as students. Some residents of this project are also involved to some extent in church activities. In general, the Spring Tree residents spend significantly more time within the residential system than is true at any of the other clusters.

All of the 10 French village residents have outside involvements, and the majority are in vocational training at the Work Activities Program (WAP) sponsored by TIRR. The others are students at the University of Houston. This group has few activities outside the residential environment beyond their daily trips to school. Occasionally, they do go by wheelchair to a nearby shopping center to eat or go shopping.

Supportive Services

At the Westbury cluster, residents contract with the Independent Life Styles Corporation to purchase shared attendant service and shared transportation. Three categories of attendant help are available based on one, two, or three hours of assistance per day. The Westbury cluster is the only one where this distinction is made, though a similar set of categories was used in the Cooperative Living project. Attendants provide assistance with personal care routines, meal preparation and clean-up, shopping, laundry, and light housekeeping. A separate individual is available for heavy housecleaning. In addition to using this shared attendant service, one resident also has a private live-in attendant because of the severity of her physical impairment (a C-1,2 spinal cord injury). A few residents do not need attendant assistance, and a few receive the help they need from spouses rather than from the shared attendant system. Most of the Westbury residents prepare at least some of their meals (often with attendant help) in their own

apartments. They eat some meals out or ask attendants to bring prepared food to the project from nearby fast food restaurants. Transportation at Westbury is provided in a Dodge van which was donated to the corporation. Most residents contract on a monthly basis for regular trips to school or work, and other errands such as shopping are worked into the schedule between regular trips. Several residents drive their own cars or vans and do not purchase transportation from the corporation.

The Free Lives Corporation provides shared attendant service and transportation to residents at Independence Hall. Attendants generally provide the same services that are available at Westbury. Many of the residents choose to eat their meals at a snack bar in the apartment complex run by Goodwill Industries, though most of them prepare some food in their own apartments (often with attendant assistance). Transportation is provided in a Dodge van owned by Goodwill Industries on a monthly contract basis, though a few residents drive their own cars.

Shared supportive services are provided at Spring Tree by the Creative Handicaps Corporation. Several of the attendants for the group as a whole live with individual residents, which is not the case at the other clusters. The services performed by attendants at Spring Tree are similar to those in the other clusters. A group of church volunteers also comes occasionally to help with cleaning. Meals are frequently prepared for a number of residents jointly in the attendant manager's kitchen, in contrast to the other clusters where individual's meals are prepared separately in their own apartments.

The Quality Living Corporation provides shared supportive services at the French Village Cluster. Attendant assistance is organized as it is in the other projects. Some residents prepare their own meals, but frequently they ask attendants to bring prepared food in. A few residents occasionally get together to prepare meals jointly in one individual's apartment. Transportation is provided on a contract basis by TIRR in a GMC step van. This arrangement is considered problematic by both parties and is viewed as temporary until the project can acquire a van of its own. The main difficulty is that the van is not available in the evenings or on weekends for non-routine trips such as shopping, errands, and leisure activities. The proximity of the cluster to a shopping center does permit both residents and attendants to make many of these trips by foot or wheelchair.

Management

At each of the clusters residents lease their apartments on an individual basis from the apartment management company. Their lease agreements are the same as those of able-bodied residents. In the three projects owned by private developers, the corporations of disabled residents have informal agreements with the property managers that allow them to select disabled persons to move into modified apartments.

The four non-profit corporations organized by residents to provide shared

services are all governed by elected boards of directors. The majority of board members are disabled residents. Control of policy thus rests with the residents themselves, though the boards usually have some members from outside the residential system. In the Independent Life Styles Corporation, two disabled residents are salaried as manager and accountant, and there is an able-bodied attendant supervisor who is responsible for the attendant staff. In the Free Lives Corporation, a disabled resident manager serves as liaison with representatives of Goodwill Industries who assist in managing the service system. An able-bodied attendant supervisor manages the attendant staff. The Creative Handicaps corporation is governed by a three-member resident council, though actual operation of the service system is directed by an LVN who has been with the original group of residents since they left their previous nursing home setting. The Quality Living Corporation is governed by a four-member council, and the attendant system is managed by an able-bodied supervisor.

The use of an able-bodied person to manage the attendant staff is a new development by contrast to the Cooperative Living service model where disabled residents themselves supervise the attendant staff. One reported advantage of this system is that firmer discipline can be exerted when the supervisor does not require attendant help. A second advantage cited is that an able-bodied supervisor can substitute for any absent employee.

Residents of the clusters who have also lived in the Cooperative Living project report that in the apartments they feel they are purchasing services on a business-like basis, whereas at the Annex they were more personally involved in the operation of the system.

Costs

The costs of living in each apartment project are summarized below.

Chart 6:3
Monthly Costs of Living in the Four Apartment Clusters

	Westbury	Independence Hall	Spring Tree	French Village
Rent	$149	$105	$100*	$105*
Meals	100	100	100	100
Transportation	50	50	-0-	65
Attendant Service	180	260	208	208
Personal Needs	130	130	130	130
TOTAL	609	645	538	$608

*2 bedroom apartment shared

Residents of each cluster meet these costs in various ways. At Westbury, a number of residents are self-supporting through their own employment.

Several persons are on full disability VA pensions or receive other veterans' benefits. Some residents are TRC clients and some receive SSI or SSDI checks. Very few of the Westbury residents receive Housekeeping and Chore Service payments from the Department of Public Welfare.

At Independence Hall, all of the residents are TRC clients. Some also receive SSI or SSDI payments. This project and Westbury are both certified as facilities by the Texas Rehabilitation Commission, so lump-sum monthly payments can be made to the corporation to purchase services on behalf of individual clients.

Residents of Spring Tree and French Village rely much more heavily on Housekeeping and Chore Service payments from DPW to meet their attendant costs. These projects are not certified as facilities by TRC, though a number of residents at French Village receive maintenance support from this agency on a direct individual basis. Most of these individuals receive SSI or SSDI payments, and many use food stamp benefits. In general, the Spring Tree and French Village residents are less financially independent of agency support than is true in the other two clusters.

Summary

Residents of the four apartment clusters are generally more fully integrated into the mainstream of society than is true in the other settings studied. Living in this environment requires a greater sense of physical security and self-sufficiency because of greater spatial isolation. Some individuals are frightened by their feelings of isolation as they first move in, but most persons who choose this setting value personal privacy over the social closeness of a dormitory or a nursing home setting.

Living in a cluster also requires an ability to manage financial resources which are limited for many disabled persons. Some individuals are unable to exercise this responsibility and have to leave the clusters for this reason. Individuals who are prone to chronic medical problems such as skin breakdowns often find it more feasible financially to live in a nursing home setting where their continued sponsorship (DPW) is not contingent upon active involvement in school or vocational training, as is the case with TRC sponsorship.

General Conclusions

Several general conclusions can be drawn from comparative analysis of alternative living environments. Each of the settings studied had an impact on both the activity patterns and the social contacts of its residents, though some settings support a wider range of lifestyles than others.

Comparative research emphasized the great significance of the relationships between handicapped persons and their attendant(s) in any living setting. Learning to manage the intensive social interaction inherent to this relationship emerged as a major concern of nearly all severely handicapped persons. Alternative ways of structuring attendant assistance had important implications for both parties.

The significance of meals differed greatly in the various environments studied. In some settings, such as the University dormitory and some apartment clusters, meals were an important focus for social interaction with friends. In other settings, however, it was major effort to arrange to get food at all and meals were not viewed as potential sources of social satisfaction.

Mobility is a major concern to almost all physically handicapped persons, and very few residents of any setting are entirely satisfied with their transportation arrangements. Because of this, the range of locations within wheelchair rolling distance of the residence seems to be of greater importance than is usually recognized. The University of Houston dormitory was most unlike the other settings in terms of residents' mobility patterns, for it provided a large and diverse environment that was almost entirely accessible by wheelchair. Ease in reaching a variety of activities without needing special transportation is a particular advantage to severely handicapped persons. The price of ready accessibility is the individual is confined to a fairly narrow range of potential social contacts in a specialized academic community.

The living settings differed greatly in the kinds of social interaction they fostered, and in the degree of integration they permitted with society at large. Some environments encouraged strong social cohesion among a group of handicapped young persons. Such cohesion was characteristic of the Cooperative Living project, the University of Houston dormitory, two of the six nursing homes, and two of the four apartment clusters, though in each of these settings a few individuals remained separate from the group. Cohesion was viewed as an important source of support by many individuals, though it also tended to foster intolerance of individuals who deviated from behavioral patterns considered acceptable by the group. In the remaining four nursing homes, young residents were virtually isolated from any social involvement. In two of the apartment clusters, residents' major social relationships were with able-bodied individuals. The apartment clusters clearly offered more opportunities to develop contacts among the general population than any of the other settings. The settings also differed

in the physical locations they offered for socialization. In almost every environment, residents expressed a desire for more outdoor space where persons could get together during leisure time.

Many handicapped individuals in each of the environments studied tended to fit a similar pattern of social development. At one point in their lives contacts with peers were important sources of social solidarity and of behavior modeling. As individuals became more experienced and confident of their abilities, they frequently outgrew this need for peer solidarity and preferred to concentrate on a smaller number of closer relationships. Some persons did not follow this pattern and in fact rejected any association with other handicapped persons because they felt it led to being stereotyped by the general population.

One of the important findings to emerge from this research was an awareness of the skills required to live independently. While many of these skills are important for all adults, they are perhaps particularly crucial for handicapped individuals because their range of adaptive options is often limited. (For example, handicapped persons usually have fewer choices of transportation than able-bodied individuals.) Three of the most important skills were found to be (a) the ability to manage social relationships with persons who provide physical assistance; (b) the ability to manage financial affairs; and, (c) the ability to locate community resources and to manage these contacts skillfully. Consideration should be given to teaching these skills more effectively in rehabilitation programs.

It is important to examine the ways in which handicapped individuals learn the skill of establishing linkages with community resources. While such linkages are often fostered by rehabilitation professionals such as social workers or counselors, their assistance can usefully be supplemented by other methods. It was found that in each of the living environments studied, certain particularly competent handicapped individuals often fill a contact brokering function for other residents. Handicapped persons isolated in settings where there are no brokers are often at a great disadvantage in trying to initiate new activities or new social relationships. There are also some programs emerging to use handicapped role models in formally structured brokering positions. Examples are consumer advocates at the Center for Independent Living at Berkeley and a community resource counselor at the University of Minnesota. Such persons provide information about whom to contact for specific services, and they also serve as models of how to manage social interaction with agency representatives.

Perhaps the major finding of the project as a whole is the need for a diversity of housing options. Different individuals are comfortable in various settings, and it is important to develop a range of choices for handicapped persons.

PART IV: EVOLUTION AND EXPANSION OF THE COOPERATIVE LIVING CONCEPT

Chapter 7: *The Apartment Clusters and The Transitional Project*

The Four Apartment Clusters

The New Options Project

The Four Apartment Clusters

Initially, it was planned that the Cooperative Living project would be a model in developing a large-scale residential facility for several hundred disabled persons. As the project developed, however, it became evident that smaller-scale projects are more feasible both economically and environmentally. Smaller-scale projects enable disabled persons to be better integrated into the general able-bodied population.

From the spring of 1974 through the fall of 1975, several small-scale projects were developed in various parts of Houston using the Cooperative Living model of supportive services, but having unique characteristics of their own. These projects were the result of the efforts of former residents in the Cooperative Living project, as well as efforts of other disabled persons in the community who became convinced that independent living arrangements with shared supportive services could become a reality for them. The catalysts in the spin-off projects were residents trained in the management programs of the Cooperative Living system.

The following time table shows the evolution of four apartment clusters in Houston:

January, 1972: Cooperative Living residential project opened in TIRR Annex facility after two years of planning; initial operational funds contributed by TIRR Auxiliary

June, 1972: Social and Rehabilitation Service R&D grant funded

Spring, 1973: Efforts initiated to find suitable physical structure for first spin-off project

Spring, 1974: First spin-off housing cluster opened at Westbury Country Village Apartments with services organized by Independent Life Styles, Inc.

Spring, 1975: Second spin-off housing cluster opened at Independence Hall Apartments, owned by Goodwill Industries, Houston, Texas, with supportive services provided by Free Lives, Inc.

Winter, 1975: Third housing cluster opened at Spring Tree Apartments with services organized by Creative Handicaps, Inc.

Summer, 1975: Fourth housing cluster opened at French Village Apartments with services organized by Quality Living, Inc.

Fall, 1975: Plans for transitional project initiated

Summer, 1976: New Options Transitional Project opened with

focus on helping severely disabled bridge gap into community and into established housing clusters

As previously noted, each spin-off program has taken on a unique legal identity, management method, consumer involvement, and financial support. Since the inception of the concept, 85 living units have been developed in the community housing clusters. Three projects, Independent Life Styles, Inc., Free Lives, Inc., and Quality Living, Inc., were developed from the initial Cooperative Living project by the 40 residents in the project study group. The fourth program, Creative Handicaps, Inc., was developed by a group of residents of a nursing home in Houston who utilized the experiences of Cooperative Living.

The management style, funding provisions, and setting for each program are described in succeeding charts 7:1, 7:2, 7:3, and 7:4.

Although each project has its own unique character, they each experienced common problems.

Issues of Location

The original goal in expanding the Cooperative Living concept was to place the projects in various quadrants of the city. This has not been achieved since the four clusters are all found in the southwest and northwest parts of the city, leaving many areas miles away from an existing program. Limitations of location are primarily due to the difficulty experienced in finding apartments that are architecturally accessible or that could be made accessible with few modifications.

Issues in Establishing and Maintaining Relationships With Apartment Owners

As new clusters were being planned, varying degrees of difficulty were experienced by the resident developers since some apartment managers were unwilling to take the "risk of having handicapped persons living as a group" in a complex of able-bodied tenants. Creating a positive relationship with apartment managers was sometimes difficult. Also, another difficulty existed because in most instances, the apartment management was requested to make architectural modifications such as widening doors, constructing ramps, remodeling baths, etc., at their own expense. In three of the four projects, once the program was underway the initial concerns of the apartment management regarding permanency of the residents, payment of rents, and community attitudes were allayed. However, in one project, the alleged behavior of the residents resulted in the management and ownership requesting that the residents vacate the complex. These problems were overcome and the project continues to function with improved relations with management, due in part to a change in apartment ownership.

Issues of Licensing

The concept of group living was plagued during early development by state laws concerning how such a program would be licensed. Licensing issues were prompted since, for the first time, severely handicapped persons were in a group living arrangement in the community, yet outside an approved

Chart 7:1

Location	Westbury Country Village Apartments
Services	Independent Life Styles, Inc.
Residents	14 units for handicapped persons 140 units for general population
Management	Non-profit corporation with handicapped residential manager and able-bodied attendant supervisor
Payment for Services	Veteran's Administration Texas Rehabilitation Commission Employment Earnings of Residents Supplemental Security Income Social Security Disability Insurance Contributions from the community
Apartment Ownership	Proprietary Newly constructed—some units modified for wheelchair accessibility

Chart 7:2

Location	Independence Hall Apartments
Services	Free Lives, Inc.
Residents	11 units for severely handicapped persons 281 units for handicapped and elderly persons
Management	Non-profit corporation manages units with attendant service in liaison with Goodwill Industries, Inc.; able-bodied attendant supervisor
Payment for Services	Texas Rehabilitation Commission Goodwill Industries, Inc. Supplemental Security Income Social Security Disability Insurance Employment earnings of residents
Apartment Ownership	Goodwill Industries, HUD funded All units wheelchair accessible

Chart 7:3

Location	Spring Tree Apartments (and Villa Madrid Apartments)
Services	Creative Handicaps, Inc.
Residents	32 units for handicapped persons 132 units for general population
Management	Consumer organized LVN coordinator as manager for handicapped units
Payment for Services	Welfare---Homemaker Chore Service Texas Rehabilitation Commission Supplemental Security Income Social Security Disability Insurance Contributions from the community
Apartment Ownership	Proprietary Apartments renovated for wheelchair occupancy

Chart 7:4

Location	French Village Apartments
Services	Quality Living, Inc.
Residents	7 units for handicapped persons 444 units for general population
Management	3 member management council; able-bodied attendant supervisor
Payment for Services	Welfare---Homemaker Chore Service Texas Rehabilitation Commission Supplemental Security Income Social Security Disability Insurance Employment Earnings of Residents Contributions from the community
Apartment Ownership	Proprietary Apartments renovated for wheelchair occupancy

institution. The issue was finally solved when it was interpreted that although the residents lived in a group, the required individual services were contracted for singly by each resident.

Issues of Financing Services

A wide range and variety of services are required by each resident in the various clusters. The nature of the services requires several state and federal programs to be meshed to accomplish necessary coverage for rent, food, transportation, attendant care, medical maintenance and personal expenses. The unpredictability of these resources continues as a major problem. Since the various sponsorships are finely tuned to accomplish coverage, the withdrawal of one sponsorship could mean that the resident has inadequate resources to remain in the cluster. Other problems result when a small increase in the benefit of one program, such as SSDI, results in the termination of SSI benefits and associated medical coverage. Problems such as these are not just associated with the development of housing alternatives, but are also found in the larger rehabilitation and community living benefits structures.

Issues of Leadership

Each cluster program resulted from the creativity and leadership of one or several residents. As expected, the development of skills in organizing a cluster came from the experience of being involved in daily management and problem-solving. In several instances, the inherent abilities existed, and the cluster developed and operated with few problems; in others, the leadership capacity has been continually developing. In three of the four clusters, the voids in resident leadership have been buffered by lay boards who provide advisory assistance.

The Transitional Project

The Cooperative Living experience helped the project staff identify important steps in the process by which handicapped persons begin independent living, increase their mobility, and expand their interactions and involvement with others. It was determined that as handicapped persons established living arrangements in the community clusters, many of the functional skills and the psychological and social coping skills that had served them well within a rehabilitation hospital, nursing home, or home setting, proved inadequate. Those persons who entered the community clusters without having benefitted from the Cooperative Living experience seemed to have more difficult and longer periods of adjustment than those who entered the clusters following their Cooperative Living involvement.

The Cooperative Living program provided the residents with a segmented introduction to the demands of independent living. For example, in most instances residents were afforded the opportunity to cope with the demands of independent living, and then consider educational and vocational demands in a timely sequence, rather than having to face and manage all matters simultaneously. The independent living, vocational and educational requirements create understandable pressures, and therefore the residents' options for coping with the demands of each are limited. Due to the

pressures of meeting the total requirements of independent living and associated economic concerns, many potentially productive persons never have a chance to become independent and they consequently retreat or are pushed into isolated environments. Still others who do try to achieve an active, productive, and independent life-style are unable to meet the demands because of the absence of a planned transition. Therefore, the New Options transitional project, now in operation at TIRR, has been established as an additional spin-off of the Cooperative Living effort. As noted above, the scope and content of the transitional project were developed from the Cooperative Living experience after observing the outcomes of individual residents (those who came through the Cooperative Living project and those who did not) and after studying the process required to accomplish their desired goals.

The elements of the transitional program include:

1. a basic residential support system that provides rooms, meals, attendant service, and transportation based on the Cooperative Living model;

2. a series of short-term training modules in areas such as attendant management, financial management, consumer affairs, social skills, family interaction, functional skills, educational opportunities, vocational opportunities, housing arrangements, homemaking skills, self-care and medical management, and sexual experiences. Other models are to be identified and developed during the course of the project;

3. a program of ongoing individual assessment and consultation with the project social worker, physical-occupational therapist, and vocational counselor in such areas as adjustment to disability, short-term and long-term goals and plans, and physical capabilities;

4. structured contacts with selected severely handicapped persons living and working in the community who will guide the individual's participation in various community activities and will serve as models of successful reintegration into society;

5. field trips and recreational activities in the community to provide a variety of socialization and mobility experiences; and

6. follow-up consultation after the participant has moved to a new living situation.

Several basic conclusions have been reached over the past five years through experiences with the various housing developments in Houston. Independent living is a feasible goal, not only for a handful of exceptional individuals, but also for many severely disabled persons who may have extremely limited physical functioning. For example, one C-1 spinal cord injured quadriplegic with an implanted breathing stimulator is attending college and has lived successfully for over two years in one of the community clusters.

It is also important to recognize the necessity of a diversity of housing options for severely disabled persons. Different individuals are comfortable in different environments, and any one individual's needs may change quite dramatically as he or she develops new capabilities. There is no single utopian solution to meet the housing and interlocked supportive service requirements of severely handicapped people.

In developing housing alternatives, it should also be recognized that one cannot wait to find an ideal physical structure, an ideal financial base, or an ideal organizational system. By adapting elements and characteristics from past successes, learning from past mistakes, and being imaginative in the process of development, the diversity and number of housing options available to persons with severe handicaps can increase.

PART V: DEVELOPING ALTERNATIVE LIVING ARRANGEMENTS

Chapter 8: *Important Dimensions and Considerations*
- Physical Structure
- Relationship to the Larger Community
- Supportive Services
- Management
- Social System
- Funding

The development of the Cooperative Living concept resulted in the definition of several comparative dimensions that significantly affected life-styles of residents.

Consideration of these dimensions is important for persons who intend to develop new housing alternatives, for rehabilitation professionals who suggest placement of clients or patients, and most importantly, for severely disabled persons who are seeking housing alternatives. It is important to recognize that the needs of physically disabled persons vary greatly depending upon such factors as degree of mobility, age, life-style before the onset of disability, family arrangements, economic levels, and traits of personality. An environment that requires great personal responsibility in managing affairs and self-confidence in being alone may seem challenging and exciting to one disabled individual, but isolated and frightening to another. Careful consideration of the factors discussed below should be useful in determining the best environment for a severely disabled person so that the individual can function comfortably at his level of independence.

Physical Structure

Careful design of spaces and fixtures can permit severely physically disabled persons to become significantly more physically independent than they are able to be in typical residential buildings. Standards for the design of accessible buildings have been published by ANSI and are currently being reevaluated in a study at Rutgers University.* Design features used most frequently are wide doorways and halls, ramped changes in level, electrical switches and outlets at waist height, bathrooms and kitchens with space for manuevering wheelchairs (often including roll-in showers), and cabinetry with space below for wheelchair accessibility and with hardware designed for persons with limited use of their hands.

Beyond this straight-forward use of design to increase physical capabilities, a structure used to house disabled persons should provide both opportunities for socialization and opportunities for privacy. Persons who are insecure when isolated from direct voice contact with other persons are more comfortable in a dormitory-style structure. Those who prefer greater privacy find apartments and single-family dwellings more comfortable and compatible with their needs. Many severely disabled persons are more sensitive to the social-contact features of a residence than are able-bodied persons because they are dependent upon the physical assistance from others, and the importance of this consideration may be much greater than is immediately apparent.

It is also important to note that the individual resident's needs change with

*Contract H-2200R, U.S. Department of Housing and Urban Development, 1975.

his or her ongoing adaptation to new circumstances. If one were to consider an individual resident over a period of time, it would be reasonable to assume that the individual would initially desire a very structured experience after his acute care and first discharge to the community, then a semi-protected dormitory arrangement, next an apartment complex with other residents, and finally, his own setting. Viewing these requirements as a continuum gives some indication of the many options in terms of privacy and socialization open to each resident as his individual needs change over a period of time.

Relationship to the Larger Community

Adaptive housing for the disabled person is usually only one of many requirements. In order to establish an independent and productive life-style, an individual also needs a number of other elements including opportunities to obtain schooling or job training, find employment, shop for material needs, pursue a variety of leisure activities, and obtain ongoing medical services. It is often preferable that sites of such activities (shopping, leisure activities, schooling) are located within wheelchair range of a residence so that individuals may reach them without arranging more elaborate transportation. A good transportation system can make the other opportunities readily available if the residence is located in a well-chosen area rather than isolated at an unreasonable distance for convenient travel. In the effort to make a wide variety of opportunities accessible, it is important to recognize that if all these opportunities are provided under one roof, the residential environment becomes a self-contained institution. Evidence indicates that most disabled persons prefer to be integrated, and meeting all of the person's needs internally prevents his or her integration into the mainstream of the community.

There is a tendency among residential planners, vocational counselors, and other professionals to believe that medical services must be an integral aspect of the residence itself. While this is undoubtedly true for some disabled persons, a great proportion of the severely disabled population can maintain stable health while obtaining needed medical services in the same way they are obtained by the able-bodied population in the community. Locating a residence too close to a medical facility may impart an institutional atmosphere that many residents purposely seek to avoid.

Neighborhood acceptance of a residence for severely disabled persons is a concern among rehabilitation professionals who feel that there will always be citizens in the community who will not approve of a special residence in their neighborhood. It has been our experience throughout the life of this project, however, that these apprehensions are over-exaggerated, and only in rare instances have citizens expressed concern over living near a group of handicapped individuals. If the resistance does become significant, it might be necessary to seek legal assistance. In most cases, however, it is possible to guard against getting into a difficult encounter with the community if a few simple steps are taken prior to the actual construction or opening of a residence.

1. It is helpful to meet with neighborhood leaders and local legislators to discuss the purpose and operating plans for the project.

2. It is important to explore with a local planning agency or zoning board the limitations that might be faced and to request a special use permit as indicated.

3. It might be impossible to receive a full or open endorsement of the project from persons in the neighborhood. Receiving a position of neutrality could very well be enough and acceptance can come after the program is operational.

Supportive Services

For many severely disabled persons, having reliable attendant assistance (as distinguished from nursing care) is a prerequisite to living outside an institution. Recruiting attendants, training them, and managing the intensive social relationships involved are major problems that continually face those who are physically dependent upon assistance. Arrangements for providing this service include a model in which each resident has one attendant, a model in which attendant service is shared among a group of residents, and a hybrid model in which one-to-one attendants are supplemented by shared attendants. In some projects, the recruiting, training, and management of attendants is done entirely by each resident. In other cases, an attendant pool may be maintained by the project to assist individuals in finding attendants. Occasionally, the project provides a staff of shared attendants and performs recruiting, training, and managing functions for the residents.

Intensive relationships between a disabled person and his attendants seem to have great potential for conflict, and most persons find it difficult to learn an appropriate interaction style, often going through a number of attendants before a stable and lasting relationship is developed. Experience in this area is often gained by living in a group residence and observing other disabled persons interact with their attendants.

Obtaining food service is another requirement of the severely disabled person. This service has been structured in various ways, ranging from having attendants prepare food in private kitchens to sharing meals in group dining facilities. The provision of meals must be considered in a more general way, since dining usually has social significance in our culture. It is therefore important to most disabled persons to consider not only the quality of food, cost effectiveness and convenience of preparation, but also the setting and context in which meals are eaten.

The availability of transportation is essential for disabled persons who wish to lead active life-styles. Shared transportation services can be organized for residential projects at various cost levels. Some projects own their own vehicles, and others use specialized transportation for the handicapped provided by other agencies. Still other residences are able to utilize the services of the City of Houston special mini-bus system, which transports

the residents from their apartments to the downtown sector of the city as well as to university and medical services.

The need for periodic medical services can also be met in various ways. Some residential projects provide medical consultation through professional staff personnel. In other cases, residents are expected to utilize the medical service systems of the community. Most disabled persons in the Cooperative Living residence managed to have their routine medical maintenance needs met by non-medical staff. Staff representing various backgrounds, many of whom had no medical or nursing familiarity, were trained to assume the necessary attendant nursing care responsibilities. Staffing with non-medically oriented personnel is very important in maintaining and promoting an atmosphere that is non-institutional in nature. Judgments regarding an individual resident's capacity to function in the setting or regarding the requirements for definitive care must, of course, be assumed by medically trained personnel. Even though daily care functions are assumed by attendants, medical care and check-ups in an outpatient facility are also essential to prevent complications. In facilities or residences where medical services are not provided internally, a resident should be encouraged to make plans in advance for coping with acute medical emergencies, and project personnel must have access to this information.

Management

In Houston projects that offer shared attendant services or attendant pools, management of the program is usually done by disabled residents, perhaps with outside supervision. This system may be overseen by a single, full-time manager, though the manager's position of authority over the staff may be weakened because he himself is dependent on their services and good will. Alternatively, various tasks, such as recruitment of personnel, accounting, or building management, may be assigned to different persons. There are many advantages in having the project managed by residents who are familiar with their own problems. In some projects, groups of residents as a whole play an active part in decision-making, effectively involving each resident in the project's operation. In others, the individual resident may purchase services and have only a business relationship with the managerial structure.

Experience has shown that several different types of management can be effective and can maintain the necessary communications with the residents under their care. It is important to be aware, however, of the strengths of the individual residents as well as the group of residents as a whole in choosing the most appropriate management style. Through the life of the Cooperative Living project, it was found that different management styles were required and depended upon the resources of the group residing in the project at a given time. For example, during some periods a necessary single manager-leader type person was required since many of the residents were not ready, able, or willing to participate in management and simply wanted services provided to them. During other times during the life of the residential program, it was found that the residents were becoming more active in the daily operation of the facility and were interested in negotiating and bringing about change in the system since it would affect

their situation personally. Overall, involving the residents in management allowed them to begin gaining skills that served them well as they began to approach competitive employment in the community. In essence, the experience as a resident manager, or an individual involved in the group management, seems to have provided a good training ground and preparation for future employment.

Social System

The social system of a residential project has a more significant impact on the life-styles of the residents than may be readily apparent. Living with other disabled persons can provide the opportunities for strengthening one's capabilities in communicating, as well as providing opportunities for modeling. Modeling was found to be particularly important for persons whose disabilities occurred after they had established a life-style as an able-bodied person. In adapting to disability, persons learn about new equipment, ways of handling medical problems such as skin breakdowns, and new physical techniques for performing various tasks through observation of fellow residents. They may also learn how to manage social interaction with attendants, potential dating partners, and personnel of various organizations such as vocational rehabilitation counselors or potential employers. Seeing a fellow resident arrange transportation for a date, open a checking account, secure a part-time job, or buy a car, may provide the motivation as well as the know-how to encourage a disabled individual to try new activities.

In a shared residence, certain roles may emerge within the social system which last beyond the tenure of a specific individual who plays the role. Some roles are specific to the project, but others seem to be more general. Among these are the role of "contact broker," who is a person experienced in dealing with outside agencies such as social security offices, university registrar's offices, housing authorities, and personnel of medical facilities. The contact broker serves an important linkage function between residents and outside agencies since he "knows the ropes" and has personal contacts which can be of great benefit to other less sophisticated residents. Another general role is that of "goat," an individual who asks for more help than the other residents feel he requires. In general, there seems to be little tolerance of such behavior in the residential settings studied, and "goats" are usually the object of joking and criticism. Ridicule of dependent behavior seems to be an important element of social interaction as it discourages dependency among other residents and supports the ideals of independence and productivity that are shared by most persons who move into independent living arrangements. Persons who are labeled as "spoiled" by other residents often can never become fully accepted members of the social system and may feel very isolated and lonely.

Group residences may become close in-groups with solidarity promoted by sharing activities such as out-trips within the community. This solidarity may be an important supportive force for many residents. In other projects, most persons "go their own way" and interact infrequently with other residents.

The social system is also important in terms of the opportunities it provides for developing external relationships. If persons are able to leave the project and become involved in activities, and if they are comfortable entertaining guests, outside friendships are developed which prevent the environment from becoming an ingrown social system.

Funding

An adequate financial base is essential for any group residence, and various combinations of sources of support have been utilized. Financial sponsorship of group projects with shared services has been provided by contributions from private individuals, by foundations, by HEW funds through Research and Training Center and Research and Demonstration grants, by establishment grants from state vocational rehabilitation agencies, and by non-profit corporations formed by groups of residents. The Department of Housing and Urban Development has provided funds to construct accessible apartment buildings but usually does not fund the necessary support services such as attendant assistance and transportation. Cash payments to individual residents may be provided by maintenance payments from departments of vocational rehabilitation, supplemental security income, or social security disability insurance. Specific services may be subsidized by homemaking and chore services from state departments of public welfare, or by rent subsidies through agreement with housing authorities. In Massachusetts, a special arrangement was developed to permit supportive services such as attendant care to be purchased under Medicare for persons in facilities other than nursing homes. Since no currently existing funding program alone provides a consolidated approach for purchase of independent living, a major task of all residential projects must be to coordinate the several sources of support that exist within state and federal agencies as well as from local programming. Development of these resources requires a considerable amount of effort, diplomacy, and continuing persistence on the part of project personnel.

EPILOGUE

Chapter 9: *The Residents Revisited*

Chapter 9: *The Residents Revisited*

Cooperative Living had a special meaning for each resident who participated in the program. To some, it meant being able to leave a nursing home or family home; to others, it provided the opportunity to go to school or consider employment. But to each resident, the Cooperative Living experience provided a setting to test his or her independence in new ways.

As a result of the Cooperative Living experience, most of the residents were able to consolidate both personal and agency resources to improve their life-styles and create options and opportunities that were not formerly available. The following case narrative describes this difficult process, and highlights the role of the Cooperative Living concept in helping integrate all the resources required to help persons achieve personal goals and expectations that are commensurate with their abilities.

John Lopez (fictitious name), a 17-year-old Mexican-American, lived with his parents and 11 siblings in a small town about 15 miles outside of Houston, where his father worked on an irregular basis. In 1965, John became quadriplegic as the result of a diving accident. John had never liked school and had just completed the eighth grade prior to his accident. His spinal cord injury, at the level of the sixth cervical vertebra, left John facing abrupt changes in his life-style.

After the accident, John was taken to a county hospital in Houston where he spent two months, and was then transferred to the Texas Institute for Rehabilitation and Research, a comprehensive medical rehabilitation facility.

During the comprehensive rehabilitation process, John benefited from a number of services beyond those required to restore function, use residual movement, and stabilize his health and physical condition. In physical therapy and occupational therapy, he learned to use his residual physical capabilities so that at discharge he could push his wheelchair on a level surface, perform grooming activities, feed himself, and write slowly using special reciprocal wrist splints. He also began some new leisure activities, including painting. Social service counseling and therapy were important in helping him resolve some of his feelings about the hopelessness of his situation and finally in working out some future plans for his life. This was tedious and often frustrating because of his precarious and uncertain physical condition and his awareness of its meaning to his survival and range of options.

After leaving the Institute, John returned to his rural

family home. His personal life centered about his brothers and cousins. Transportation out of his isolated setting was seldom available for a wheelchair-dependent person. As a result, in spite of his earlier dislike of education, John developed an interest in reading which became his major pastime. During the next seven years, John lived with his family and returned to the Institute every six months to be followed in outpatient clinics.

John eventually became dissatisfied with his existence and sought a vocational evaluation to explore other alternatives. This examination revealed an intellectual potential for college and also indicated that with proper equipment, John now had enough hand and arm function to perform some manual shop tasks. He was accepted as a client of the Texas Rehabilitation Commission (TRC) and made the decision to enter a work adjustment and vocational training program at the Institute's Work Activities Program.

In order to begin involvement in vocational training, John had to find a living arrangement in Houston, since his family was unable to provide daily transportation. Initially he agreed to live in a nursing home which had other young disabled residents, and where shared transportation would be available. He had strong feelings of dread about moving to this environment, and it was a difficult compromise to make. Fortunately, before he entered the nursing home, an opening became available in the Cooperative Living project. John moved into the project in the fall of 1973, and began to reassess his personal goals. Following extensive vocational exploration, in January, 1974, he entered a training program in micrographics developed by the Work Activities Center.

The contacts John experienced with young, active, working disabled persons and the availability for social and vocational involvement stimulated important changes in his lifestyle. In May, 1974, John moved into an apartment cluster with shared attendant and transportation services developed as an outgrowth of the residential program. At this time (December, 1976), he is living with a significant other in this setting.

After being employed a year and a half in the micrographics project, John decided to enter the University of Houston where he is presently enrolled, and plans to graduate soon.

John's needs for a complex array of rehabilitation services during the years since his injury have varied greatly as his

personal development has evolved. Without the availability and appropriate coordination and timing of a number of key elements of comprehensive rehabilitation, such as medical restorative services, follow-up services, adaptive housing, vocational evaluation and training, attendant assistance, and transportation, John's progress would have been stifled. Access to only one of these elements would have been of little benefit.

In this case example, it becomes clear that understanding and negotiating services, many with conflicting entitlements, was essential for success. Also, the timely availability of a housing alternative in the sequence of events was extremely important. Without the Cooperative Living alternative, it is questionable whether the goals of independent living, involvement in school and work, and active social participation would have been attainable.

The Cooperative Living concept, which combines physical arrangements and assures personal physical assistance, vocational training experiences, and personal growth services, must be a part of the rehabilitation process that extends beyond the formal institution. The full impact of this concept is further illustrated by a follow-up study conducted in January, 1977, on the 40 residents who participated in the Cooperative Living project.

In the follow-up study, it was determined that one resident had died, and three were lost to follow-up, giving a reportable N of 36. Thirty-three of the 36 persons interviewed now live in urban settings, and three reside in rural homes. Of the 33 persons living in urban settings, 17 currently live in apartment clusters with shared services, four reside with personal attendants in apartments or apartment clusters, five reside with their spouses in apartments or apartment clusters, three live in homes with their spouses, one person lives in his own home with an attendant, two residents have returned home to their families, and one person currently resides in a nursing home.

The current mean income level of the residents has increased from $122.59 at admission to the project to a current mean of $496.91. This increase is primarily due to the active vocational involvement of 17 former residents. Chart 8:1 lists the job classifications and reports full and part-time employment.

Chart 8:1
Current Job Classifications of Former Cooperative Living Residents

Part-time	Full-time
1 — real estate salesperson	2 — switchboard operators
1 — writer	1 — intermediate school teacher
1 — products salesperson	1 — receptionist
1 — communications clerk	1 — accountant
	1 — civil engineer
	1 — social work administrator
	1 — vocational evaluator
	1 — products salesperson
	1 — research director
	1 — college professor
	2 — residential managers
n = 4	n = 13

Of the 19 persons who are not employed, 13 are attending college or are involved in vocational training, and six persons are inactive. Two are inactive due to medical problems, and four are in the process of reformulating plans.

Chart 8:2 offers a comparison of the residents' sources of income at admission with current sources. Several significant conclusions can be drawn. The employment status, both full and part time, demonstrates that employment gains were maintained. Secondly, the role of Vocational Rehabilitation in the process of helping residents achieve vocational independence was successful; therefore, vocational rehabilitation support has decreased from 15 persons being sponsored at admission to seven at the time of the follow-up study. Thirdly, the dependence on state welfare programs, Supplemental Security Income, and Social Security has decreased from 37 persons being sponsored to 24 currently receiving these types of benefits. Finally, the shift in dependence from parents is significant from the standpoint of individual independence.

Chart 8:2
Residents' Sources of Income

	ADMISSION	CURRENT STATUS
EARNINGS		
Part Time	1	4
Full Time	0	13
SOCIAL SECURITY	17	9
SUPPLEMENTAL SECURITY INCOME	4	15
STATE VOCATIONAL REHABILITATION	15	7
HOUSING AUTHORITY	0	0
VETERAN'S ADMINISTRATION	1	1
STATE WELFARE	16	0
PARENTS	28	2
SPOUSE	0	3
OTHER (Investments, etc.)	3	3

The follow-up study also included a question about the former residents' feelings about their current life-styles and their future goals and plans. Thirty-one of the residents indicated that they are content with their current life-styles, four feel their life-styles could be improved, and one

person indicated dissatisfaction with his life-style. When asked about future goals or plans, 12 persons expressed a desire to go to work, nine said they wanted to complete their education or vocational training and begin work, six wanted to obtain a higher degree or pursue a post-graduate professional degree (i.e., law), two said they would like to purchase a car, and six persons indicated that they had achieved their goals and were content. Four persons had no future plans or goals.

The findings in this follow-up study serve to reinforce the permanance of the benefits of the Cooperative Living experience upon individual residents. The Cooperative Living model offers hope for the disabled segment of our population. The experience in Houston, Texas, only serves to typify the need existing across the nation for unique living arrangements for the severely handicapped. Independent living for the severely disabled must become the rule, not the exception, in the United States. The Cooperative Living concept can serve as a national model for residential developments of this type. Therefore, the significance of this venture and others to follow can only be measured after viewing the opportunities offered.

APPENDICES

Appendix A: *Vignettes*

Vignettes of Residents as They Entered the Cooperative Living Project

Case Number 1

Date entered project—3/72 | Age at entrance into project—23
Date left project—1/73 | Sex—M Marital status—S

Disability:	SCI* at C-5
Cause of disability:	Trampoline accident
Age at onset of disability:	14 years
Educational level at admission:	15+ years
Living arrangements at admission:	Nursing home
Occupation at admission:	Student
Level of personal income at admission:	$24.00/mo.

Case Number 2

Date entered project—1/72 | Age at entrance into project—26
Date left project—8/73 | Sex—M Marital status—S

Disability:	SCI at C-4,5
Cause of disability:	Football injury
Age at onset of disability:	19 years
Time since onset of disability:	6 years, 3 months
Educational level at admission:	15+ years
Living arrangements at admission:	Urban home
Occupation at admission:	Student
Level of personal income at admission:	$87.40/mo.

Case Number 3

Date entered project—1/72 | Age at entrance into project—24
Date left project—7/74 | Sex—M Marital status—S

Disability:	SCI at C-5,6
Cause of disability:	Football injury
Age at onset of disability:	17 years
Time since onset of disability:	6 years, 2 months
Educational level at admission:	14+ years
Living arrangements at admission:	Urban home
Occupation at admission:	Student
Level of personal income at admission:	0

*Spinal Cord Injury

Case Number 4

Date entered project—1/72
Date left project—4/74

Age at entrance into project—26
Sex—M Marital status—S

Disability:	SCI at C-6
Cause of disability:	Water sking accident
Age at onset of disability:	24 years
Time since onset of disability:	2 years, 6 months
Educational level at admission:	13 years
Living arrangements at admission:	Rural home
Occupation at admission:	Unemployed
Level of personal income at admission:	$233.10/mo.

Case Number 5

Date entered project—1/72
Date left project—8/73

Age at entrance into project—23
Sex—M Marital status—S

Disability:	SCI at C-6,7
Cause of disability:	Football injury
Age at onset of disability:	16 years
Time since onset of disability:	6 years, 3 months
Educational level at admission:	14+ years
Living arrangements at admission:	Urban home
Occupation at admission:	Student
Level of personal income at admission:	$150.00/mo.

Case Number 6

Date entered project—1/72
Date left project—4/74

Age at entrance into project—23
Sex—M Marital status—S

Disability:	SCI at C-6,7
Cause of disability:	Diving accident
Age at onset of disability:	16 years
Time since onset of disability:	6 years, 4 months
Educational level at admission:	15 years
Living arrangements at admission:	Urban home
Occupation at admission:	Student
Level of personal income at admission:	$50.00/mo.

Case Number 7

Date entered project—6/72
Date left project—6/73

Age at entrance into project—24
Sex—F Marital status—S

Disability:	SCI at T-5
Cause of disability:	Automobile accident
Age at onset of disability:	23 years
Time since onset of disability:	1 year
Educational level at admission:	12 years
Living arrangements at admission:	Rural home
Occupation at admission:	Unemployed
Level of personal income at admission:	$122.60/mo.

Case Number 8

Date entered project—3/72 | Age at entrance into project—20
Date left project—4/74 | Sex—F Marital status—S

Disability:	SCI at T-10,11
Cause of disability:	Spinal tumor
Age at onset of disability:	16 years
Time since onset of disability:	4 years
Educational level at admission:	12 years
Living arrangements at admission:	Rural home
Occupation at admission:	Unemployed
Level of personal income at admission:	$50.00/mo.

Case Number 9

Date entered project—9/72 | Age at entrance into project—21
Date left project—8/74 | Sex—M Marital status—S

Disability:	SCI at C-5,6
Cause of disability:	Automobile accident
Age at onset of disability:	16 years
Time since onset of disability:	5 years, 2 months
Educational level at admission:	14 years
Living arrangements at admission:	Urban home
Occupation at admission:	Student
Level of personal income at admission:	0

Case Number 10

Date entered project—9/72 | Age at entrance into project—23
Date left project—9/74 | Sex—M Marital status—S

Disability:	SCI at C-5
Cause of disability:	Automobile accident
Age at onset of disability:	18 years
Time since onset of disability:	4 years, 10 months
Educational level at admission:	16 years
Living arrangements at admission:	Urban home
Occupation at admission:	Student
Level of personal income at admission:	$100.40/mo.

Case Number 11

Date entered project—1/72 | Age at entrance into project—29
Date left project—6/73 | Sex—M Marital status—S

Disability:	SCI at C-5,6
Cause of disability:	Diving accident
Age at onset of disability:	20 years
Time since onset of disability:	8 years, 9 months
Educational level at admission:	15 years
Living arrangements at admission:	Urban home
Occupation at admission:	Student
Level of personal income at admission:	$210.00/mo.

Case Number 12

Date entered project—4/72 Age at entrance into project—21
Date left project—3/73 Sex—F Marital status—S

Disability:	Arthritis quadriplegia
Cause of disability:	Congenital
Age at onset of disability:	11 years
Time since onset of disability:	12 years
Educational level at admission:	12+ years
Living arrangements at admission:	Nursing home
Occupation at admission:	Unemployed
Level of personal income at admission:	$180.00/mo.

Case Number 13

Date entered project—5/73 Age at entrance into project—22
Date left project—4/74 Sex—M Marital Status—S

Disability:	SCI at C-5
Cause of disability:	Helicopter crash
Age at onset of disability:	20 years
Time since onset of disability:	2 years
Educational level at admission:	12 years
Living arrangements at admission:	Urban home
Occupation at admission:	Unemployed
Level of personal income at admission:	$1500.00/mo.

Case Number 14

Date entered project—5/73 Age at entrance into project—18
Date left project—8/73 Sex—M Marital status—S

Disability:	SCI at C-6,7
Cause of disability:	Diving accident
Age at onset of disability:	14 years
Time since onset of disability:	3 years, 9 months
Educational level at admission:	11+ years
Living arrangements at admission:	Urban home
Occupation at admission:	High school student
Level of personal income at admission:	0

Case Number 15

Date entered project—6/72 Age at entrance into project—23
Date left project—9/72 Sex—M Marital status—S

Disability:	SCI at C-5,6
Cause of disability:	Diving accident
Age at onset of disability:	21 years
Time since onset of disability:	1 year, 1 month
Educational level at admission:	16 years
Living arrangements at admission:	Urban home
Occupation at admission:	Unemployed
Level of personal income at admission:	$150.00/mo.

Case Number 16

Date entered project–1/72 | Age at entrance into project–20
Date left project–3/74 | Sex–M Marital status–S

Disability:	SCI at C-6,7
Cause of disability:	Diving accident
Age at onset of disability:	19 years
Time since onset of disability:	1 year, 9 months
Educational level at admission:	13 years
Living arrangements at admission:	Urban home
Occupation at admission:	Student
Level of personal income at admission:	$238.00/mo.

Case Number 17

Date entered project–8/73 | Age at entrance into project–25
Date left project–4/74 | Sex–M Marital status–S

Disability:	SCI at C-5
Cause of disability:	Diving accident
Age at onset of disability:	16 years
Time since onset of disability:	8 years, 2 months
Educational level at admission:	8 years
Living arrangements at admission:	Rural home
Occupation at admission:	Unemployed
Level of personal income at admission:	$79.00/mo.

Case Number 18

Date entered project–8/74 | Age at entrance into project–20
Date left project–9/74 | Sex–M Marital status–S

Disability:	SCI at C-4
Cause of disability:	Automobile accident
Age at onset of disability:	16 years
Time since onset of disability:	4 years
Educational level at admission:	13 years
Living arrangements at admission:	Urban home
Occupation at admission:	Student
Level of personal income at admission:	$93.34/mo.

Case Number 19

Date entered project–8/73 | Age at entrance into project–25
Date left project–8/75 | Sex–M Marital status–S

Disability:	SCI at C-5,6
Cause of disability:	Automobile fell on back
Age at onset of disability:	15 years
Time since onset of disability:	9 years
Educational level at admission:	13 years
Living arrangements at admission:	Nursing home
Occupation at admission:	Student
Level of personal income at admission:	$25.00/mo.

Case Number 20

Date entered project—11/73 Age at entrance into project—20
Date left project—8/75 Sex—M Marital status—S

Disability:	SCI at C-5
Cause of disability:	Diving accident
Age at onset of disability:	17 years
Time since onset of disability:	1 year, 11 months
Educational level at admission:	12 years
Living arrangements at admission:	Nursing home
Occupation at admission:	Unemployed
Level of personal income at admission:	$123.00/mo.

Case Number 21

Date entered project—12/73 Age at entrance into project—20
Date left project—9/75 Sex—M Marital status—S

Disability:	SCI at C-5,6
Cause of disability:	Fall
Age at onset of disability:	18 years
Time since onset of disability:	2 years, 6 months
Educational level at admission:	12 years
Living arrangements at admission:	Rural home
Occupation at admission:	Unemployed
Level of personal income at admission:	$250.00/mo.

Case Number 22

Date entered project—1/74 Age at entrance into project—23
Date left project—3/75 Sex—M Marital Status—S

Disability:	SCI at C-6
Cause of disability:	Automobile accident
Age at onset of disability:	20 years
Time since onset of disability:	3 years, 2 months
Educational level at admission:	13 years
Living arrangements at admission:	Rural home
Occupation at admission:	Student
Level of personal income at admission:	$86.67/mo.

Case Number 23

Date entered project—4/74 Age at entrance into project—23
Date left project—8/75 Sex—M Marital status—S

Disability:	SCI at C-4,5
Cause of disability:	Motorcycle accident
Age at onset of disability:	20 years
Time since onset of disability:	3 years
Educational level at admission:	12 years
Living arrangements at admission:	Nursing home
Occupation at admission:	Student
Level of personal income at admission:	$390.00/mo.

Case Number 24

Date entered project–8/74
Date left project–9/74

Age at entrance into project–20
Sex–M Marital status–S

Disability:	SCI at C-4,5
Cause of disability:	Automobile accident
Age at onset of disability:	19 years
Time since onset of disability:	1 year
Educational level at admission:	12 years
Living arrangements at admission:	Hospital
Occupation at admission:	Unemployed
Level of personal income at admission:	0

Case Number 25

Date entered project–5/74
Date left project–9/75

Age at entrance into project–24
Sex–M Marital status–S

Disability:	Disability:SCI at C-5,6
Cause of disability:	Automobile accident
Age at onset of disability:	21 years
Time since onset of disability:	3 years, 6 months
Educational level at admission:	12 years
Living arrangements at admission:	Rural home
Occupation at admission:	Unemployed
Level of personal income at admission:	169.00/mo.

Case Number 26

Date entered project–7/74
Date left project–7/75

Age at entrance into project–31
Sex–F Marital status–S

Disability:	Polio paraplegia
Cause of disability:	Viral infection
Age at onset of disability:	Child
Time since onset of disability:	29 years
Educational level at admission:	12 years (GED)
Living arrangements at admission:	Rural home
Occupation at admission:	Unemployed
Level of personal income at admission:	$195.00/mo.

Case Number 27

Date entered project–8/74
Date left project–9/75

Age at entrance into project–19
Sex–M Marital status–S

Disability:	SCI at C-4,5
Cause of disability:	Football accident
Age at onset of disability:	15 years
Time since onset of disability:	4 years, 10 months
Educational level at admission:	11+ years
Living arrangements at admission:	Urban home
Occupation at admission:	High school student
Level of personal income at admission:	0

Case Number 28

Date entered project–10/74 Age at entrance into project–26
Date left project–1/75 Sex–M Marital status–S

Disability:	Polio quadriplegia
Cause of disability:	Viral infection
Age at onset of disability:	2 years
Time since onset of disability:	24 years, 4 months
Educational level at admission:	19+ years
Living arrangements at admission:	Urban home
Occupation at admission:	Student
Level of personal income at admission:	$200.00/mo.

Case Number 29

Date entered project–7/74 Age at entrance into project–29
Date left project–9/75 Sex –M Marital status–S

Disability:	Polio quadriplegia
Cause of disability:	Viral infection
Age at onset of disability:	6 years
Time since onset of disability:	24 years
Educational level at admission:	13+ years
Living arrangements at admission:	Urban home
Occupation at admission:	Student
Level of personal income at admission:	$200.00/mo.

Case Number 30

Date entered project–7/74 Age at entrance into project–25
Date left project–9/75 Sex–M Marital status–S

Disability:	SCI at C-5
Cause of disability:	Diving accident
Age at onset of disability:	18 years
Time since onset of disability:	8 years
Educational level at admission:	12+ years
Living arrangements at admission:	Urban home
Occupation at admission:	Student
Level of personal income at admission:	$237.03/mo.

Case Number 31

Date entered project–2/73 Age at entrance into project–20
Date left project–4/74 Sex–M Marital status–S

Disability:	SCI at C-5,6
Cause of disability:	Gun shot wound
Age at onset of disability:	15 years
Time since onset of disability:	3 years, 10 months
Educational level at admission:	12 years
Living arrangements at admission:	Urban home
Occupation at admission:	Unemployed
Level of personal income at admission:	85.00/mo.

Case Number 32

Date entered project–1/72
Date left project–2/74

Age at entrance into project–24
Sex–M Marital status–S

Disability:	SCI at C-5,6
Cause of disability:	Automobile accident
Age at onset of disability:	20 years
Time since onset of disability:	2 years, 10 months
Educational level at admission:	15 years
Living arrangements at admission:	Nursing home
Occupation at admission:	Student
Level of personal income at admission:	$214.40/mo.

Case Number 33

Date entered project–1/72
Date left project–7/74

Age at entrance into project–26
Sex–M Marital status–S

Disability:	SCI at C-4,5
Cause of disability:	Football accident
Age at onset of disability:	16 years
Time since onset of disability:	10 years, 6 months
Educational level at admission:	16 years
Living arrangements at admission:	Nursing home
Occupation at admission:	Unemployed
Level of personal income at admission:	$24.00/mo.

Case Number 34

Date entered project–10/73
Date left project–4/74

Age at entrance into project–22
Sex–F Marital status–S

Disability:	SCI at C-5,6
Cause of disability:	Automobile accident
Age at onset of disability:	16 years
Time since onset of disability:	5 years, 7 months
Educational level at admission:	13 years
Living arrangements at admission:	Rural home
Occupation at admission:	Unemployed
Level of personal income at admission:	-0-

Case Number 35

Date entered project–4/73
Date left project–4/74

Age at entrance into project–20
Sex–F Marital status–S

Disability:	SCI at C-5,6
Cause of disability:	Diving accident
Age at onset of disability:	17 years
Time since onset of disability:	2 years, 7 months
Educational level at admission:	12 years
Living arrangements at admission:	Rural home
Occupation at admission:	Unemployed
Level of personal income at admission:	$50.00/mo.

Case Number 36

Date entered project—6/73 Age at entrance into project—19
Date left project—10/73 Sex—F Marital status—S

Disability:	Polio paraplegic
Cause of disability:	Viral infection
Age at onset of disability:	2 years
Time since onset of disability:	17 years, 9 months
Educational level at admission:	12 years
Living arrangements at admission:	Rural home
Occupation at admission:	Unemployed
Level of personal income at admission:	$379.00/mo.

Case Number 37

Date entered project—11/74 Age at entrance into project—19
Date left project—9/75 Sex—F Marital status—S

Disability:	Polio quadriplegic
Cause of disability:	Viral infection
Age at onset of disability:	One year
Time since onset of disability:	19 years
Educational level at admission:	12 years
Living arrangements at admission:	Rural home
Occupation at admission:	Unemployed
Level of personal income at admission:	$97.00/mo.

Case Number 38

Date entered project—6/74 Age at entrance into project—33
Date left project—9/75 Sex—F Marital status—S

Disability:	Myelo-dysplasia
Cause of disability:	Congenital
Age at onset of disability:	Birth
Time since onset of disability:	33 years
Educational level at admission:	14+ years
Living arrangements at admission:	Urban home
Occupation at admission:	Unemployed
Level of personal income at admission:	$12.00/mo.

Case Number 39

Date entered project—3/75 Age at entrance into project—26
Date left project—9/75 Sex—M Marital status—S

Disability:	SCI, hemi-para
Cause of disability:	Automobile accident
Age at onset of disability:	23 years
Time since onset of disability:	3 years
Educational level at admission:	12 years
Living arrangements at admission:	Nursing home
Occupation at admission:	Unemployed
Level of personal income at admission:	$181.00/mo.

Case Number 40

Date entered project–6/74 Age at entrance into project–23
Date left project–8/75 Sex–M Marital status–S

Disability:	Chondro-osteodystrophy
Cause of disability:	Congenital
Age at onset of disability:	11 years
Time since onset of disability:	12 years
Educational level at admission:	12 years
Living arrangements at admission:	Rural home
Occupation at admission:	Unemployed
Level of personal income at admission:	$98.10/mo.

Appendix B: *Operational Aids*

The TIRR residential project is a housing program especially designed to meet the physical, psycho-social, vocational, and economic needs of severely physically disabled young adults. The program is supported by the residents themselves as well as by various state and federal agencies.

The Institute subscribes to and complies with the provisions of the Civil Rights Act of 1964, offering equal opportunity employment without regard to race, creed, national origin, sex, or age.

This pamphlet includes a job description, a discussion of employee benefits, a list of grounds for dismissal, information about pay scales, and additional information about your job with the residential program. Employees are expected to fulfill the requirements of their assigned job classification.

MANAGEMENT OF THE PROJECT

Operation of the facility and supervision of staff are managed by the resident management council made up of four elected representatives of the resident population. This council makes up monthly work schedules which are posted on the staff bulletin board. They handle any organizational problems that occur and resolve grievances that arise among staff members or residents. The resident management council periodically evaluates the performance of staff members and gives due consideration to additional compensation. They interview prospective employees, make needed additions to the staff, and make any necessary terminations.

STAFF FACILITIES

Orderly Room: Employees may use the orderly room as a staff lounge. However, they are expected to answer call lights on signal.

Bulletin Board: All established schedules, meeting notices, and employee notices are posted on the staff bulletin board.

Sign-in Sheets: All employees should sign the sign-in sheet when they arrive for work and when they leave. Be sure to have someone initial your times and total your hours.

Meal Periods: All full-time employees are given a thirty minute meal period per regular work day. Food trays may be ordered from the Institute food service. Any accrued meal costs are deducted from your pay check.

COMPENSATION

Salary is quoted in terms of a monthly rate and is computed and paid on the basis of an hourly rate with a total of twenty-six (26) pay periods during the year.

Compensation example: An employee with a monthly salary of $440.00 earns $5,280.00 per year. To determine the amount of each pay check, this annual salary is divided by 26 to arrive at a gross amount of each check, in this case, $203.07.

Payday is every other Thursday. If a holiday falls on Thursday, pay checks will be distributed on the preceeding day. The Institute does not issue pay checks to employees in advance of regularly scheduled paydays.

Each pay check will include all earnings due for the two-week period ending on the previous Sunday.

Income tax, Social Security, insurance and other approved deductions such as Credit Union, United Fund and parking are deducted as authorized by the employee. These deductions are itemized in the pay check stub for the employee's records.

A shift differential of 10% of base pay will be paid to all employees who work the evening or night shifts, beginning not earlier than 2:45 pm. This differential is paid only for time actually worked. No differential addition will be paid for vacations, holidays, sick leave, or any other paid time off.

Salary advances or loans on salary are not permitted.

OVERTIME

Overtime will not be paid unless it is authorized in advance by the department heads or their representatives. Overtime is normally defined as all hours worked in excess of forty (40) hours per week and is paid at the rate of one and one-half (1½) times the regular hourly rate of pay for all non-exempt employees.

PERSONAL TIME OFF

Employees requiring time off for personal business shall (1) make up such time within the same week, (2) charge such time against earned vacation, or (3) take as time off without pay.

TERMINATION

Two-weeks notice of voluntary termination is required for the employee to be eligible to receive accumulated vacation pay. Notice should be submitted to the department head. I.D. cards, name badges, and keys issued must be surrendered at a termination interview. Final pay checks are held until all Institute property is returned or paid for.

DISMISSAL

Improper personal conduct for cause, on the part of any employee, may result in immediate dismissal with all benefits forfeited. Grounds for such dismissal include but are not limited to the following:

1. Physical mistreatment or verbal abuse of residents.
2. Mistreatment, willful neglect or damage to the residents' or Institute's property.
3. Continued or gross neglect of duty.
4. Fighting or possession of weapons.
5. Unauthorized possession of, or being under the influence of, alcohol or drugs.
6. Falsification of records: patient, hospital, personnel or employment application.
7. Misrepresentation of qualifications, certification, etc.
8. Dishonesty, theft, or other immoral conduct.

9 Failure to give immediate notification of absense from work.

10 Willful negligence or refusal to perform duties in the assigned manner.

11 Leaving assigned work area without permission.

12 Misuse of supplies or equipment.

13 Unexcused absences or chronic absenteeism.

14 Unauthorized eating or drinking of Institute food.

15 Continuous violation of parking regulations.

16 Willful violation of personnel policies.

GRIEVANCES

Personnel problems will be resolved by discussion with the resident management council.

Employee Discounts: In the event an employee should require or desire the specialized services of the Institute on an in-patient or out-patient basis, including out-patient therapy or diagnostic tests, a 50% discount is granted.

A discount of 20% is granted to dependents who are members of the employee's immediate family.

A discount of 10% is granted to all employees and their immediate family who purchase prescription drugs at the Institute.

Annual Chest X-Ray: The Institute provides, at no cost to the employee, an annual chest X-ray. Employees are requested to comply with the notice when received.

EMPLOYEE BENEFITS

Holidays: The holiday schedule for full-time employees, approved by the Administration, is published at the beginning of each year. The following is a list of approved paid holidays:

New Year's Day
Memorial Day
Independence Day
Labor Day
Thanksgiving
Floater holiday (chosen each year)
Christmas

When New Year's and Christmas fall on Tuesday through Friday, an additional one-half day is granted on New Year's and Christmas Eves.

To be entitled to holiday pay or time off in place of holiday pay, a full-time employee must work on the last scheduled work day prior to and immediately following the holiday unless his absence is authorized or excused by his immediate supervisor.

Employees working in a 24-hour coverage area shall be scheduled for that holiday, or 30 days before or after the holiday. Holidays shall not be accumulated.

Vacation: Ten days of paid vacation are earned by full-time employees after completion of each full year of employment. Vacation time may not be taken during the first six months of employment, but can be taken as earned thereafter, at the discretion of the department head.

Paid vacation taken during the first year will be deducted from the final pay check of the employee who fails to complete one full year of service.

After five full years of employment, one additional day per year is earned, up to fifteen days. Completion of twenty years of service entitles employees to twenty paid days or four calendar weeks of vacation.

Vacation will not be paid if taken before earned. This would be leave without pay.

Vacation time cannot be accumulated and must be taken within twelve months after completion of the year for which it is earned.

Vacations are scheduled within and by the departments and are subject to department responsibilities and change. Longevity will be considered in scheduling vacations.

An extra day is added to vacation time if a holiday falls within the vacation period.

Maternity Leave: A maximum of three months' leave without pay for maternity is provided without loss of benefits for those employees expressing a desire in writing to return to work. Vacation time may be used as part of maternity leave; however, sick leave time may not be used for such leave.

Medical-Surgical Insurance: Blue Cross-Blue Shield and Major Medical Insurance is provided for all permanent full-time employees. The Institute bears the major portion of the cost of this program. The effective date of coverage is the first day of the month following employment. Dependents may be enrolled at the employee's expense.

The hospital room allowance is $25.00 per day for 365 days. Most additional costs while hospitalized are paid in full.

A $100.00 deductible applies before Major Medical benefits begin, which the employee is obligated to pay. After the $100.00 deductible has been satisfied, the Major Medical Insurance covers 80% of the cost, and the hospital room allowance increases to $40.00 per day.

Life Insurance: After six months of continuous service as a permanent full-time employee, a term life insurance policy is issued with the cost of this coverage paid by the Institute.

Retirement: The Institute provides a retirement plan for all permanent full-time employees, the eligibility for which begins after three years continuous employment. This is a non-contributory plan with the Institute bearing the full cost.

The employee earns a 10% vested interest after nine years of service. This increases each year at the rate of 10% a year until the employee attains 100% vested interest at the end of 18 years of continuous service.

The normal retirement age is 65. No benefits are paid until retirement.

Tax Deferred Annuity Program: Federal legislation enables employees of most non-profit organizations to set aside dollars and reduce their current taxes at the same time through a tax deferred annuity plan. The Institute provides all employees the opportunity to participate in such a plan on a voluntary basis after six months of continuous service.

Credit Union: Through its membership in the Texas Hospital Association, the Institute is able to provide employees with a convenient means of saving and obtaining loans at low interest rates through the Texas Hospital Association Credit Union. All employees are eligible for membership in the Credit Union at a cost of $6.00 each. Interest on savings is paid quarterly.

To obtain an unsecured loan, an employee must work full time, be at least 21 years of age and have been employed three consecutive months.

Sick Leave: Ten days of paid sick leave (.84 day per month) are earned by each full-time employee after completion of each full year of employment. Compensation for illness extended beyond accumulated sick leave time will not be paid.

Unused sick leave is accumulated to a maximum of sixty days for protection of income in case of major illness.

Employees who are absent because of illness must notify their department head promptly in order that their work may be handled during their absence. At the discretion of the department head, employees who call in to report illness after the beginning of their work shift or regular work day will not be paid sick leave for that day.

It is also the employee's responsibility to keep his department head informed regarding an expected date of return to work. Presentation of a doctor's statement indicating the nature and length of illness and permission to return to work may be required by the department head.

Employees are encouraged to make physicians and dental appointments outside working hours. When this is not possible, sick leave may be granted at the discretion of the department head.

On termination, accumulated sick leave will not be paid.

Death in Family: Up to three days leave with pay may be given for death in the immediate family (mother, father, mother-in-law, father-in-law, grandmother, grandfather, brother, sister, husband, wife, or children) to include the day of the funeral.

Jury Duty: Time off with full pay will be granted for jury duty. A certificate issued by the Clerk of the Court will be necessary to verify days to be paid.

Military Leave: Time off with compensation for military reserve duty will be granted for a maximum of two weeks. Compensation will be an amount equal to the difference of military pay and normal salary. A copy of appropriate orders must be on file with the Personnel Department to receive pay.

Leave of Absence: All leaves of absence (leave without pay with no forfeiture of benefits previously earned) require prior approval by the Administration.

transportation

DATE_____

TIME	PASSENGERS	FROM	TO
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830			
900			
900			
930			
930			
1000			
1000			
1030			
1100			
1130			
1200			
1230			
100			
100			
130			
130			
200			
200			
230			
230			
300			
300			
330			
330			
400			
400			
430			
430			
500			

night activities sheet

Time	To Bed	Shower	Bullet	MISC.
5:00				
5:30				
6:00				
6:00				
6:30				
6:30				
7:00				
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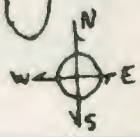
11:30				
12:00				

Turning Schedule	
Name	Time

GET UP SHEET





ME	WAKE UP	GET UP	SHOWER	BULLET	DESTINATION
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:30					
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7:30					
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Attendant Job Description

The TIRR residential services program is a complete living arrangement designed to meet the basic needs of a group of handicapped young adults. The concept of independent living is supported by a system of assistive services provided by a staff of non-professional aides and attendants.

The duties and responsibilities of the aides and attendants are:

1. To assist in activities such as:

    showering
    dressing and undressing
    bowel and bladder programs
    transferring
    changing and caring for urinary devices
    emptying and cleaning leg bags and bed bags
    serving and setting up food trays

2. To provide assistance in the following housekeeping services in each individual room:

    laundry (wash, dry, fold)
    bed making
    straightening of personal articles in room

3. To accept responsibilities of general building maintenance by:

    emptying trash cans in orderly room and recreation room
    keeping tables in cafeteria clear of trash and trays
    keeping halls, recreation room, and orderly room clean and clear of trash
    keeping utility room clean

All established schedules, such as shower schedule, laundry schedule, transportation schedule, get-up sheet, and evening activity sheet should be followed carefully and should not vary except in emergency situations.

All requests for assistance by the residents should be promptly considered and carried out without delay.

When not busy with resident assistance, all staff members should stay in the hall so that lights can be answered without delay.

Driver/Orderly Duties and Responsibilities

1. To drive residents to and from school, work, job interviews, clinic, doctor and dentist appointments, and other necessary appointments.

2. To keep accurate daily records of mileage traveled by each resident, destination and/or purpose and which vehicle was used in each trip.

3. To work with residents and management in coordinating schedules for school and work.

4. To assist orderlies (in orderly capacity) when not involved with transportation.

5. To run personal errands for residents when there is spare time between necessary trips (previously scheduled trips described in no. 1).

6. To assist residents in maintenance of their vehicles—taking vehicle to and from service departments, inspection stations and automotive parts stores; changing license plates; cleaning interiors of trash and/or dirt and mud accumulation while transporting residents.

   Small and minor repairs can be made on vehicle if time permits and task does not require that driver become too soiled.

Appendix C: *Resident Agreement*

Resident Agreement

As a resident of Cooperative Living—Texas Institute for Rehabilitation and Research, I,

_____

agree to abide by and comply with the attached House Rules, Statement of Financial Responsibility, and Statement of Service Charges.

I understand that I will be evaluated after my first three months of residence at the Annex, and if I am not then employed, in school, or otherwise productively occupied, I may be asked to leave the Annex.

I hereby agree to the above conditions set forth in this contract. I understand that failure to meet my responsibilities will result in termination of all services provided by Cooperative Living and the Texas Institute for Rehabilitation and Research.

_____ _____

Date Signature

House Rules

1. Possession of or consumption of non-prescription narcotics and/or misuses of prescription drugs is forbidden.

2. At all times a person shall conduct himself with consideration toward his or her fellow residents and staff. Repeated violation of this consideration such as abuse of personal property abuse of the living facilities (indoors and outdoors), unnecessary use of staff, continued disturbances of fellow residents, or any other conduct that is detrimental to the facility or the residents in general can be cause for eviction.

Guests will also be required to abide by these rules or expect to be barred from the premises.

Financial Responsibilities of Residents

A deposit of $100 will be required from all residents when they move in. This amount will be refunded when the individual leaves if he or she gives two weeks notice of departure and if there has been no damage to the room.

All rents and services are expected to be paid one month in advance. A grace period of 60 days from the date the bill is due will be given those residents whose continuous income is disrupted for temporary sickness, temporary loss of job, etc. In these instances, at the end of the first 30 day delinquent period, justification for failure to make payment shall be discussed with the management council. Any back expenses not paid after 60 days will be discussed with the management council which will review the financial status of the resident, whereupon agreement to a promissory payment schedule will be set up. Failure to meet these payments will be cause for eviction.

ATTENDANT SERVICE

Three categories of attendant service are $120, $190, and $210 per month. Assignment to categories is based on the amount of time each resident requires from an assistant. When new residents enter the project, the Resident Management Council will estimate the amount of service required, and assignment to a category will be made. If this initial category assignment is inappropriate or if the individual is able to decrease the amount of assistance required, appropriate adjustments will be made in future billings.

Assignment to categories is made on the basis of the number of services required by each resident from the following list: (a) getting up and dressed, (b) going to bed and undressing, (c) transferring from bed to wheelchair and vice-versa, (d) preparation for shower, showering or washing hair, (e) feeding, (f) turning at night, (g) day rest, (h) transfer to and use of commode chair. Those residents who require one to four services are in category 1, those who require five to six services are in category 2, and those who require seven to eight services are in category 3.

TRANSPORTATION

A charge of $40 per month is made for transportation by van to attend school, work, or clinic appointments and to pick up supplies. Additional trips for recreational purposes or shopping may be scheduled as the availability of the van and driver permits.

RENT

Rent charges are $110 per month for single rooms and $55 per resident for doubles.

MEALS

An estimated cost for food will be billed to each resident monthly for meals eaten at the project. If the amount charged is more than the amount actually consumed, appropriate adjustments will be made in future billings.

Appendix D: *Interview Schedule*

Date:_____ Residence:_____

Residential Environments for Persons With Physical Disabilities

Name:_____ Telephone:_____

Address:_____ Date entered present residence:_____

_____

Marital status:_____ Age:_____

Ethnic group:_____ Sex:_____

Level of education: (highest grade completed) _____

Religious preference:_____

Father's occupation:_____

Mother's occupation:_____

Marital status of parents:_____ Number of siblings:_____

Level of family income per year:

less than $3000
$3000–$4999
$5000–$6999
$7000–$8999
$9000–$10999
$11000–$14999
$15000–$20000
over $20000

Disability: _____

Cause: _____

Date of onset: _____ Number of years since onset: _____

Rehabilitation program: location _____

duration _____

Hospitalizations since discharge from initial rehabilitation program (please indicate number in each category):

urological	skin breakdown
respiratory	re-evaluation and follow-up
neurological	other (please specify)
orthopedic	

Please indicate the approximate number of contacts you have had in the past year with each of the following services:

hospitalization	occupational therapy
emergency room care	speech pathology
physician	social service
nursing service	psychological services
urological technician	vocational evaluation and counseling
physical therapy	other

Are there certain medical problems that you have frequently?

Do you have insurance coverage for medical expenses?
What type?

How do you regularly manage each of the following activities?

RESPONSES

1 managed by individual without difficulty

2 problematic, but managed by individual

3 individual requires some assistance from others

4 individual depends entirely on others

ACTIVITIES

dressing	mobility with wheelchair
grooming	transportation
eating	management of financial affairs
bathing	management of medications
bowel needs	food preparation
bladder needs	shopping for groceries
writing	other shopping
transferring	other (please specify)

Please indicate the special equipment you use:

1 orthotic device(s)	5 special driving equipment
2 standard wheelchair	6 trapezes for transferring
3 electric wheelchair	7 respiratory equipment
4 commode/shower chair	8 other (please specify)

Have you learned any new physical capabilities since leaving a rehabilitation program?

Type of residence:_____

Others living in this residence:_____

Please indicate how the following services are provided:

ATTENDANT SERVICES

1 family or friends

2 nursing home staff

3 private attendant salary per month_____

4 cooperative attendant service

5 other (please specify)

How would you evaluate this arrangement for providing attendant services?

TRANSPORTATION

1 family or friends

2 self-owned vehicle drive yourself? transfer yourself?

3 specialized transportation service

4 public transportation

5 other (please specify)

Do you feel your transportation needs are adequately provided for?

FOOD

1 family or friends

2 nursing home food service

3 other food service

4 commercial restaurants

5 other (please specify)

Is this arrangement satisfactory?

What factors were important in your decision to live in this residence?

What factors determine your daily schedule (what time you get up, eat your meals, go to bed, etc.)?

Do the architectural features of this residence meet your needs? If not, what needs are unmet?

How would you evaluate this setting as a residential environment for physically disabled persons?

Have the other persons living here influenced you? In what ways?

Do conflicts ever arise between the persons who live or work here? What are the causes of conflict?

What would you consider an ideal residential arrangement for yourself now? What arrangement would you consider ideal on a long-term basis? Would you prefer to live in a setting only for handicapped persons, with a mixed handicapped and able-bodied population, or with only able-bodied persons?

What are your approximate monthly expenses in each of the following categories?

EXPENSE	AMOUNT	PAID BY
housing		
food		
attendant services		
transportation		
medications and supplies		
other medical expenses		
leisure activities		
other expenses (please specify any other major expenses such as car payments, insurance costs, college tuition, etc.)		

Please indicate the amount of your monthly income in each category:

earnings

social security

supplemental security income

veterans benefits

state welfare

state rehabilitation

parents

spouse

other (please specify)

TOTAL MONTHLY INCOME

Would you describe what your lifestyle was like before the onset of your disability?

What have you done since the onset of your disability?

Activities II

Current activities:

1 at home

2 school_____ hours carrying now_____

3 job position_____

firm_____

hours worked per week_____

4 training program

5 other (please specify)

Has your present residential arrangement had an effect in determining the activities you are able to undertake?

Are there other things you would like to be doing if you had the opportunity?

Have you made long-range plans for your life? Were these affected by your disability?

What activities make up your usual weekly routine?

MONDAY

TUESDAY

WEDNESDAY

THURSDAY

FRIDAY

SATURDAY

SUNDAY

Leisure Activities

Please indicate the kinds of leisure activity you take part in:

ACTIVITY	OTHER PARTICIPANTS	FREQUENCY OF PARTICIPATION	TRANSPORTATION

Did your leisure activities change significantly as a result of your disability?

Would you like to get out more? What kinds of additional activities interest you? What are the major factors, if any, that hamper your social activity (cost, lack of transportation, not enough friends, etc.)?

How did you get to know your set of friends?

residential proximity to parents' home

residential proximity to your home

high school contacts

college or vocational school contacts

job contacts

membership in organizations

shared leisure-time interests

rehabilitation contacts

military service

family friends

friends of spouse

persons you met
through other friends

other (please specify)

Are you generally satisfied with your set of friends? Would you like to develop more friendships with persons your own age, with persons of the opposite sex, with able-bodied persons?

Who are your closest friends?

How would you characterize your relationship with your family?

How would you characterize your relationship with persons who provide attendant services for you?

What are your feelings about social situations with other disabled persons present? Do you prefer to interact with disabled persons, with able-bodied persons, or do you not have a preference?

Do you consider prejudice against the disabled to be an important problem? In what circumstances (jobs, social relationships, etc.)? Have you encountered this prejudice yourself? Have your decisions about the activities you want to pursue been affected by this social prejudice?

What are your feelings about the present system of providing financial assistance to persons with physical disabilities? What changes would you recommend in this support system?

How would you evaluate the choices of housing available to disabled persons? What additional alternatives would you like to have? Should disabled persons be integrated into the able-bodied population as fully as possible, or is it better for them to live clustered together? Why?

Traditionally the nuclear family has been an important element of American social structure with a large proportion of the population choosing to get married and have children. Do you think you would have followed this pattern if your disability had not occurred? Has your disability changed your feelings about marriage and children?

Do you feel you have changed as a person as a result of your disability? In what ways?

produced by:

composition & design department
division of education
texas institute for rehabilitation & research
houston, texas

editor: janet bost
design &
production: laurel richards,
laurie gerken
printing: ann brinkmann,
lavaun shropshire
paper: monarch papers, inc.
text: mountie warm white,
cover: peninsular light blue

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